# DÆDALUS

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## LIVING WITH AIDS

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JOURNAL OF THE AMERICAN ACADEMY OF ARTS AND SCIENCES

# Living with AIDS

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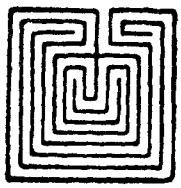

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# Preface to the Issue "Living with AIDS"

THIS ISSUE OF *DÆDALUS* BEARS A TITLE that deserves to be taken seriously. "Living with AIDS" is an idea that emerged gradually as a consequence of a number of individuals meeting to discuss what an issue of *Dædalus* on the subject of AIDS might most appropriately treat. There was no interest in doing again what others have already done; the literature on AIDS is today substantial. Our own interest in the subject grew out of a conviction that a different sort of agenda needed to be set, to put the AIDS phenomenon in a perspective that had not yet been considered.

Because events move swiftly in the contemporary world, it is easy to forget that AIDS is a phenomenon of the 1980s. The identification of the retrovirus that causes the disease, the course of the infection, and the modes of its transmission—these are all matters about which we knew very little when the disease first surfaced in the early 1980s and was spoken of as a disease of gay men. All that we know about AIDS today we have learned in the past eight years, although it rests on important scientific knowledge acquired earlier. Without the earlier discovery of retroviruses, the agency that causes the infection would have been an even greater mystery, exacerbating the fears about this "new disease" that have existed almost from the beginning.

For those preoccupied these last years with the disease—and their number is today legion, and not only in the scientific, medical, and health-care communities—this has been a time of extraordinary and impressive discovery but also of immense and nearly continual frustration. However gratified some may be by certain of these discoveries, it is generally agreed that we are only at the very



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beginning of a scientific investigation that will go on well into the twenty-first century, that may not quickly yield even the more limited information or results that are hoped for.

However much we may have learned about the virus and its mutations, we are still very far from having developed a cure for those who have become infected, the greatest number of whom, because of the long asymptomatic incubation period, are not yet showing the symptoms of the disease. Nor, for that smaller number already seriously ill with full-blown AIDS, have we discovered therapies to prolong life or reduce suffering for more than a short time.

As for a vaccine to protect those not now infected, all researchers agree that given the nature of the virus and what we know about it today, such a development, if it ever occurs, may be many decades away. There is no early prospect of a "magic bullet" to protect against AIDS infection.

In these circumstances, if we are to learn how to think about AIDS, recognizing some of its present dangers to individuals and society, and being concerned, very properly, with its possible future course, we must be willing to confront situations that are, for many, both novel and disquieting. That the infection is already so widespread, touching many of the most developed societies, including the United States, today one of the epicenters of the disease, while also gravely afflicting many regions in the less developed world, and not only in Africa, makes this a bewildering international public-health development. It is made all the more complex by the different populations it affects.

Because all agree that the greatest number of those who carry the AIDS virus today are not yet showing symptoms of the disease, and may not do so for some time, perhaps for as long as ten or more years, the incidence of the disease, as we now perceive it in the hospitals and clinics of the world, is but a tiny fraction of what it is likely to be in the 1990s. Whether one accepts the figure that tens of millions are already infected in the world—with several million being HIV-positive in the United States—or whether one wishes to believe these numbers to be somewhat exaggerated, no one disputes the fact that the greatest number of those who harbor the virus do not now know they do. Their number is substantially larger than the number of overt AIDS cases.

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If the latter are already severely taxing the capacities of health care and if other social-welfare facilities are wholly unprepared for a disabling infectious disease of this magnitude and character, now afflicting so many young people, the prospect for the near future is still more disconcerting. Even if new drugs and other therapies were developed quickly and made available at reasonable cost, they would be out of the reach of a great many. In the most favorable scenario now imaginable, just helping to prolong the lives of those who are infected would be a remarkable feat of medical research. It would certainly alleviate many problems that now exist, including the fear of testing by those who imagine themselves to be infected and who see no advantage in learning the bad news early when so little can be done to help them.

Yet, even such relatively optimistic scenarios, and there are others, do not suggest that a cure is imminent. In the opinion of certain medical researchers, AIDS may become a new and serious chronic disease, not totally different from any number of others that now exist and are susceptible to drug and other therapies. Indeed, we may, in the foreseeable future, witness medical interventions of a kind not now known, to arrest certain of the more debilitating and life-threatening conditions produced by AIDS.

In the interim—which may prove to be a long one—we live with a disease that is incurable, that clearly has a long incubation period and is almost certainly already lodged in millions throughout the world who will one day show the symptoms of their condition. How are we to prepare for what awaits them? How are we to care for them? What can we do to minimize the risk of new infections? How, given all reasonable prognoses, can we prepare individuals and societies for the hazards that are impending?

Less than two years ago, at an AIDS conference in Talloires, France, I asked how the great powers in the First World War might have acted if those in responsible political and military positions had been able to understand that there was no possibility of the war being rapidly won, and had they been able, confronted with this information, to conceive of what 1915, 1916, 1917, and 1918 would bring. Would the policies pursued that led to the needless slaughter of millions of young men and untold suffering among millions of civilians, men and women, have been averted or in some way attenuated? Since such foresight is always uncommon, and since the

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analogy, however dramatic, is not a wholly compelling one for societies that persist in believing—despite all the evidence to the contrary—that AIDS is not yet the national (or international) catastrophe that some now predict, the incentives for elaborate planning seem minimal.

Because long-range planning is uncongenial to so many, the use of the World War I analogy, implying that we might be in the first year of a "war" likely to become more fierce and more deadly, has not been wholly persuasive. Another kind of analogy then suggested itself to the conference. Why not acknowledge that AIDS, a new infectious disease, wholly unanticipated and wholly unprepared for, required new kinds of political, intellectual, and social organization? In the early 1980s, most people, asked whether a new infectious disease would ever again surface, would probably have denied the possibility. In that happy age, so confident of all that science and medicine had done to eradicate or treat infectious disease, it was assumed, at least in the developed world, that most serious infectious disease could be cured. The twentieth-century medical research miracle that had made population growth possible, that had extended life expectancy and vastly reduced infant mortality, was thought to be impervious to sudden shock.

Such innocence, interestingly, had never existed with respect to war. The explosion of atom bombs over Japan and the subsequent development of thermonuclear weapons instructed the world in one fundamental fact: the danger of war had not diminished. Indeed, many believed that such danger had escalated because of American-Soviet rivalry, but also because of the possibility of the proliferation of thermonuclear weapons and the threat of sudden attack. New thought was held to be necessary on the causes of war, the hazards peculiar to thermonuclear warfare. The urgency of all these problems, not to speak of many others, helped create what came in time to be called an arms control community, men and women committed to the idea of thinking about the unthinkable—worldwide nuclear devastation and destruction. That prospect recommended the mobilization of new intellectual resources and, what is more important, the conceptualization of conditions and situations inconceivable in a time of "conventional" weaponry.

As early as 1960, *Dædalus* contributed to the creation of this arms control community by providing a forum where such issues could be

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probed in a novel way. It was possible, of course, to go on talking about disarmament in the manner that had become common in the 1920s and 1930s, but the distance between thermonuclear and conventional warfare required that combat and defense be wholly reconceived, that a new concept—that of arms control—be invented. This happened both intellectually and politically in the early 1960s, first in the United States.

As the AIDS crisis developed, an analogy suggested itself to those who were familiar with the arms control phenomenon. Was AIDS not clearly an infectious disease that held alarming possibilities, with major social and economic dislocation becoming almost certain? If one considered also the political hazards of a widespread epidemic, thought to be brought on by the habits of populations for which there was scant sympathy, the potential for new kinds of public outrage and persecution seemed enormous. Given the rapidly growing perception that the AIDS crisis was something more than a public-health menace, of significance principally to medical researchers, physicians, nurses, social workers, and the like, the idea grew that the mobilization of new resources to study AIDS and to combat the disease deserved high priority. The analogy with the study of arms control seemed suddenly apposite. Why not undertake investigation, drawing on many professions and academic disciplines, that might even go under the name of "AIDS Control," that would have as its principal purpose the articulation of new policies?

The idea sufficiently commended itself to make it seem reasonable for *Dædalus* to apply to the John D. and Catherine T. MacArthur Foundation for support. The arms control analogy seemed promising. In 1960, in his foreword to the *Dædalus* "Arms Control" issue, Jerome Wiesner had written:

> This issue of *Dædalus* . . . attempts to provide some of the basic information and understanding needed for an intelligent public discussion of the disarmament problem.

If the last words of that sentence were altered to read "the AIDS problem," this would give an explicit rationale for a new kind of study. Dr. Wiesner's additional remarks, as carried in the 1960 *Dædalus* volume, gave even more compelling reasons for such inquiry; he had said:

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> To a distressing degree American citizens, who insist on free and open discussion of important issues facing their country, have turned away from the problems of arms control as being of such complexity and requiring access to so much secret military and political information as (supposedly) to be beyond the comprehension of the ordinary citizen. But, without a widespead understanding of the options available to the nation and without some ability on the part of the general public to judge the relative security of various alternatives, it will not be possible for the United States to find acceptable arms-limitation agreements or to accept the constraints such agreements will impose on the military activities of the country.

Again, an easy transposition suggested itself. In writing to the MacArthur Foundation, it seemed reasonable for me to say:

> In the case of AIDS, the reason for turning away from the problems of AIDS control, if there has indeed been such a turning away, and some would say that there has been, is not that the problems are complex, or that they require access to secret information. Rather, in this instance, the fact of the matter is that the problems are immensely sensitive, that they touch interest groups that are enormously powerful, that they deal with issues that are intensely personal, that have social implications of the gravest sort. In this situation, we like to believe that we are open about everything, when indeed we are remarkably discreet about most things. We see very easily that a country like Zaire does not wish certain kinds of information to be propagated, but we do not see the mote in our own eye, and we fail to realize how very reticent we are in our discussion of the problem of AIDS. When I say "we," I mean not only individuals, but very established institutions, including the most prominent universities, the media, elected officials, and many others.

My peroration followed, almost automatically:

> . . . it is absolutely essential that we establish what we in fact know about this disease today, what we now see as the major prospects for its cure, but, most importantly, how we perceive the moral, social, economic, political, and other problems that are already presenting themselves as very serious.

Never deluding ourselves that we could win support for such a project simply by arguing for its analogies with something like arms control, we were convinced there was a need to develop questions appropriate to the subject, absolutely central to any broad-based

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inquiry about AIDS. Disinclined to treat AIDS simply as a scientific or a medical problem, though both were obviously principal concerns, we felt there was a desperate need to place AIDS in a context that would allow difficult and sensitive questions to be raised, that would call for a kind of candor that was still uncommon in any mass-media treatment of this personal and communal tragedy.

In my correspondence with the MacArthur Foundation, questions about AIDS poured forth:

> What do we know about its origins? What are the theories that are gaining acceptance in the scientific community? What other theories exist? What more do we want to know, and why is it urgent that we know more? Who is inquiring into all this, and what prospects are there for significant new knowledge being acquired soon? What are the impediments to new inquiry in the matter of origins? How much do these touch on sensitive political, national, and other feelings?
>
> What do we know today about the transmission of AIDS? What did we think about this issue of transmission a few years ago? Have there been some major recent discoveries? How reliable are the statistics on the spread of the disease? Given that it is asymptomatic, are the figures that we have on those who carry the virus at all reliable? Of those who now carry the virus, how many are expected to develop cases of full-blown AIDS? Why do we believe those numbers? What are the most plausible theories about why heterosexuals in Africa are so affected? What reasons do we have for confidence that heterosexual transmission will not soon become common in the United States and in Europe? What do we know of the conditions that exist in Asia, particularly in countries like the Philippines, Indonesia, Thailand, and the like? How reliable are the statistics we have even for those countries that claim to be reporting on all the cases that they have? Who is involved in studying the issue of transmission, and what are the centers of research in this area that most need support?
>
> What are the most common projections for the next five years? For the next decade? Who has made these projections? What confidence do we have in them? Are there many reticences in respect to the likely spread of the disease? Ought we to respect these reticences? Why? What price do we pay for these reticences? How well are the various AIDS educational programs working? How well are they working with homosexuals, with drug addicts, with others? Are we satisfied that we are reaching exposed groups like prostitutes and others who are fairly

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promiscuous in their sexual behavior? Who, particularly among the young, appear to be at risk and are not being sufficiently attended to? Who is resisting much of this educational program, dismissing the directive to use condoms as propaganda? What is the basis for the resistance to the provision of clean needles to drug addicts? Who are the silent individuals in all this, and what institutions are choosing not to speak out? Have we any notion of why more information would be better, or why discretion in much of this may be recommended? Is it significant that certain churches have remained fairly silent on the issue and that even the universities have not spoken out in the way that one might expect them to? Do we really understand the significance of these reticences or of the rejection of some of the common wisdom that now exists on the subject?

What are some of the principal scientific and medical findings of the past twelve months that need to be acknowledged as significant? What laboratories are being looked to for further developments? Is there evidence that one or two theories about cause, transmission, and remedy have gained particular credence in the last year or so? Is the research effort still too limited, and if so, what needs to be done? Are the research funds inadequate? If they were increased, what should they be committed to? Is the number of professionals available to study these problems still too small? Is there any prospect for growth in cooperation among scientific institutions concerned with AIDS? Does cooperation depend on much closer international collaboration, and can we really foresee collaboration in respect to AIDS? Is AIDS still being seen too much as a disease like others that have existed before? Is too much effort being made to find cures for those who are uninfected, when equal efforts need to be made to find cures for those who already carry the virus? Is the detection and treatment of these individuals not one of the highest priorities? What can be done to make those who are already afflicted cooperate in very important research enterprises? Individuals talk about a national campaign comparable to that which produced flight to the moon or other comparable technological breakthroughs. Is all this "rhetoric" mass-media "hype"? Do we not require wholly different models for national and international cooperative efforts? In short, are we misconstruing the kind of thing that needs to be done, the agencies that ought to be doing it, the forms of collaboration that will be necessary if some control of the disease is to be effected in the foreseeable future?

Are we being sufficiently aware of the moral dilemmas that are already being created by the disease? Are we prepared for those that will almost

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certainly arise if the disease continues to spread dramatically? Do we know why certain policies are already being taken, why certain policies are being defended in the way that they are? How do these questions relate to such fundamental issues as compulsory testing, quarantining of the infected, and the like? What are we going to do if we are obliged to care for hundreds of thousands, including many infants and young children? How does their infection provide us with the opportunity to ameliorate the stigma that now attaches to the disease, that is so incontestably important in governing what people are prepared to do about it, and indeed the ways in which they are prepared to involve themselves in helping to curb it? Which among the moral agencies of our society need to be persuaded to be more forthright on the issue, to make their views known and join in a dialogue that is still too muted? Will the issue of AIDS not almost certainly come out of such political agitation? Do we already see many expressions of political distress in the world, with panaceas offered that are retrograde, dangerous, and unlikely to achieve their purpose?

What about likely economic consequences? Are we at all satisfied with the estimates that we now have of what AIDS care is going to cost in terms of hospital and medical expenses? What consequences do we foresee for employment, and what are the best minds who are addressing this question saying? Do we realize what may be impending for private insurance systems and other organizations that are responsible for the care of those who become ill? What do we know about the social consequences of the disease today? Are we thinking sufficiently about what the social consequences will be if the numbers grow substantially for the individual, the family, and other institutions? Is this not a matter that merits reflection, not only because new policies are demanded but because we have to think of how such policies can be justified and ultimately implemented?

AIDS has created great fears in certain elements of this society. Some of them are quite legitimate; others are not. Is it possible to reduce them? How? Who understands the peculiar and complex anxieties of today and how they can be allayed? Or is it important that some of them not be allayed? Indeed, is fear itself, in this instance, something that can serve useful purposes, or is any such view heretical and nonsensical? Do the hospitals and medical-care systems of many countries need to be substantially revamped? To achieve what ends? Must we think of wholly new kinds of hospitals for AIDS patients, and is it well that we should think of these being developed exclusively for such patients? What new types of training need to be developed for those who will

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care for these patients? What about the uninfected who remain at considerable risk? What needs to be done for them, by medical systems, to encourage them to be tested, to desist from certain dangerous practices? Are we satisfied with the success of any of those who have made this their primary purpose? What evidences of this success can we point to?

What about the legal systems of many countries in the world? How much is law likely to be used to protect the individual, the group, the larger society? Have we reflected on how this epidemic could impose new strains on our systems of justice and on our prison systems more generally? Is the whole question of AIDS and justice one that we continue to evade? How can we begin to grasp the proper dimensions of the subject?

Do we have sufficient information about how various national societies are responding to this situation? Do we have criteria for saying that some are handling the problem more efficiently and more humanely than others? What approaches seem to be the most reasonable? How much do they reflect value systems that are common in countries where there is a good deal of irrational fear and prejudice? What international comparisons need to be made? Do we have any systems to measure those that are doing well as distinct from those that are doing badly?

When the *Dædalus* planning groups eventually met—a MacArthur Foundation grant having made this possible—it was agreed that no single study could possibly treat so vast and undifferentiated an agenda. Some of the issues, in the opinion of many who attended, were clearly less central than others. They might be safely set aside. However, our most interesting and animated discussions centered on what the purpose of the study ought to be, how the agenda could be crafted to achieve a reconceptualization of the hazard of AIDS, of what might be learned from this terrible human tragedy and not simply about the infectious disease itself.

While the planning groups were avid in supporting the dissemination of every kind of useful knowledge—believing that the attention of the mass media had rarely communicated the real political, moral, and social dilemmas created by the disease—their single most important concern was to show how AIDS, in its complex effects, had challenged any number of accepted notions about why individuals, institutions, and communities comport themselves as they do. No one was heartless enough to suggest that the calamity provided an

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incomparable opportunity to study national and international politics, but some such idea insinuated itself as we reflected on how certain professions and bureaucracies attempted to cope with problems for which there were no adequate guidelines.

As the discussions proceeded over many days, in large conferences and in smaller, less disciplined settings, two things became apparent. First, the term *AIDS control* was an unacceptable one. It had connotations that were too restrictive. Because AIDS will be with us for the rest of our lives—because it is extremely doubtful that the virus itself will soon (or ever) be wholly eradicated—the condition both today and for the foreseeable future is more accurately conveyed by the words *living with AIDS*.

Today we live with AIDS in much the same way as we live with thermonuclear weapons. Neither is likely soon to disappear from the scene. The question, then, becomes one of determining how the disease can be lived with, how those who are now ill and those who are not but soon will be are to be cared for. How can those who are uninfected remain so? What specific social conditions need to be attended to if the spread of the malady is to be contained? What hopes are there for behavior change that will make new infection unlikely? What institutional changes need to be considered if we are serious in our determination to curb the spread of the disease? Most importantly, what do we need to know that we do not now know if we are to cope with the serious social and economic problems created by AIDS? What do we need to say loudly that is now only whispered because gouty toes are likely to be stepped on, because candor in respect to an issue as sensitive as AIDS is enormously hazardous and always in short supply?

As the planning groups built on these discussions, interest in the personal and social devastation the illness creates grew; so also interest grew in the fear and resentment AIDS generates and the suffering it inflicts. How could one hope to do these many things, showing a concern also with the politics and public-policy implications of the disease, never ignoring the sustaining institutions on which those who are already ill increasingly depend? To realize, also, that this disease, a tremendous challenge to the scientific and medical communities, poses equally bewildering dilemmas for those in other disciplines, compelled to advise on sensitive issues that are extraordinarily divisive, suggests why so many retreat into the safety of

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ideological platitudes. Whether the subject be sex or drug use, AIDS has made the easy choices of yesterday seem suddenly inadequate, irrelevant. It is not surprising that we have not been able to do justice to the subject in a single *Dædalus* issue. This is the first of two issues to be entitled "Living with AIDS."

A great many debts have been incurred in the process of planning these *Dædalus* issues. Those who helped in the more formal planning, both as authors and planners, are listed in the advisory group. In addition, in more informal meetings in Paris, London, and New York, there was an opportunity to consult with those who could not attend our meetings in Cambridge. I am grateful to all who were prepared to advise and to comment on what others said.

Without the help of the John D. and Catherine T. MacArthur Foundation, this enterprise would never have been launched. I feel great gratitude to those who saw the possibilities of the approach taken. Because the international dimensions of the problem were always seen to be primary, it was vital to involve individuals from outside the United States. Air fares, and not only those from distant points, are today very steep. The American Foundation for AIDS Research provided a grant that made such international travel and participation possible. It was crucial to our endeavor.

Finally, I must thank the Program in Science, Technology, and Society of the Massachusetts Institute of Technology, not only for the help given by Dr. Kenneth Keniston but also for its generous financial support, which was given to honor the late Dr. Robert Morison. Dr. Morison, a former Vice President of the American Academy of Arts and Sciences, a member of the Board of Editors of *Dædalus*, a frequent contributor to our pages, and guest editor of at least two of our volumes, was a man devoted to the kinds of research and reflection that are represented in this volume and in the one scheduled to follow. It was difficult, in life, to thank him adequately for all that he did over several decades to help *Dædalus*. It is a pleasure to honor his memory with this small expression of appreciation and gratitude.

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*Charles E. Rosenberg*

# What Is an Epidemic? AIDS in Historical Perspective

WE USE THE TERM *epidemic* in a variety of ways—most of them metaphorical, moving it further and further from its emotional roots in specific past events. Even in relation to health, we employ the word in contexts decreasingly related to its historical origins. Medical historians speak of an epidemic of tuberculosis in Europe between 1700 and 1870 and of an epidemic of rheumatic fever in the century and a quarter after 1800. In the mass media every day, we hear of "epidemics" of alcoholism, drug addiction, and automobile accidents.[1] These clichéd usages are disembodied yet at the same time tied to specific rhetorical and policy goals. The intent is clear enough: to clothe certain undesirable yet blandly tolerated social phenomena in the emotional urgency associated with a "real" epidemic.

Defining aspects of that millennia-old reality are, of course, fear and sudden widespread death. It is plague and cholera, yellow fever and typhus that we associate viscerally with the experience of epidemics, not alcohol and automobiles. AIDS has reminded us forcefully of that traditional understanding. But there is another defining component of epidemics that needs emphasis, and this is their episodic quality. A true epidemic is an event, not a trend. It elicits immediate and widespread response. It is highly visible and, unlike some aspects of humankind's biological history, does not

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proceed with imperceptible effect until retrospectively "discovered" by historians and demographers.

Thus, as a social phenomenon, an epidemic has a dramaturgic form. Epidemics start at a moment in time, proceed on a stage limited in space and duration, follow a plot line of increasing and revelatory tension, move to a crisis of individual and collective character, then drift toward closure. In another of its dramaturgic aspects, an epidemic takes on the quality of pageant—mobilizing communities to act out proprietory rituals that incorporate and reaffirm fundamental social values and modes of understanding. It is their public character and dramatic intensity—along with unity of place and time—that make epidemics as well suited to the concerns of moralists as to the research of scholars seeking an understanding of the relationship among ideology, social structure, and the construction of particular selves.

For the social scientist, epidemics constitute an extraordinarily useful sampling device—at once found objects and natural experiments capable of illuminating fundamental patterns of social value and institutional practice. Epidemics constitute a transverse section through society, reflecting in that cross-sectional perspective a particular configuration of institutional forms and cultural assumptions. Just as a playwright chooses a theme and manages plot development, so a particular society constructs its characteristic response to an epidemic.

Contemporary America's experience with AIDS has already provided materials in abundance for analysis based on such assumptions. In many ways we have reenacted traditional patterns of response to a perceived threat. But if we are to understand our contemporary reaction to a traditional stimulus, we must distinguish between the unique and the seemingly universal, between this epidemic at this time and this place and the way in which communities have responded to episodic outbreaks of fulminating infectious disease in the past. We have become accustomed in the last half century to thinking of ourselves as no longer subject to the incursions of such ills; death from acute infectious disease has seemed—like famine—limited to the developing world. Life-threatening infectious ills had become, almost by definition, amenable to therapeutic or prophylactic intervention. AIDS has reminded us that this sense of assurance might have been premature, the attitudinal product of a particular historical

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moment. AIDS has shown itself both a very traditional and a very modern sort of epidemic, evoking novel patterns of response and at the same time eliciting—and thus reminding us of—some very old ones.

## EPIDEMIC INCIDENT AS DRAMATURGIC EVENT

The narrative of Camus's *Plague* begins on a strikingly circumstantial note. "When leaving his surgery on the morning of April 16, Dr. Bernard Rieux felt something soft under his foot. It was a dead rat lying in the middle of the landing. On the spur of the moment he kicked it to one side and, without giving it a further thought, continued on his way downstairs."[2] The dead rat symbolizes and embodies the way in which epidemics seemingly begin with minor events—little noticed at the time, yet often revealing in retrospect. The rat's plague-stricken body underlines as well the way in which man is bound in a web of biological relationships not easily comprehended or controlled. From a very different point of view, it also illustrates the way in which the implacable circumstantiality of an epidemic coexists with—in fact necessarily invokes—larger frameworks of meaning. The peculiar texture of any epidemic reflects continuing interaction among incident, perception, interpretation, and response.

No matter what Camus's philosophical intentions, he chose to embed that intellectual agenda in the morally and historically resonant structure of an ongoing epidemic. And his narrative in fact follows closely the archetypical pattern of historical plague epidemics.[3] Like the acts in a conventionally structured play, the events of a classic epidemic succeed each other in predictable narrative sequence. The first of these acts, which I term progressive revelation, turns on the initial appearance and gradual recognition of the intruding disease.[4]

### *Act I. Progressive Revelation*

Like the citizen of Camus's plague-stricken Oran, most communities are slow to accept and acknowledge an epidemic. To some extent it is a failure of imagination; perhaps even more it is a threat to interests, to specific economic and institutional interests and, more generally, to the emotional assurance and complacency of ordinary

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men and women. Merchants always fear the effect of epidemics on trade; municipal authorities fear their effect on budgets, on public order, on accustomed ways of doing things.

Only when the presence of an epidemic becomes unavoidable is there public admission of its existence. Bodies must accumulate and the sick must suffer in increasing numbers before officials acknowledge what can no longer be ignored. The pattern has repeated itself in century after century. Whether in early modern Italy, seventeenth-century London, or nineteenth-century America, whether the unwelcome visitor was plague, yellow fever, or cholera, the first stage of an epidemic acts itself out in predictable fashion. Physicians find a few "suspicious" cases and then either suppress their own anxiety or report their suspicions to authorities, who are usually unenthusiastic about publicly acknowledging the presence of so dangerous an intruder.

The stakes have always been high, for to admit the presence of an epidemic disease was to risk social dissolution. Those who were able might be expected to flee contaminated neighborhoods, while men and women remaining in stricken communities could be expected to avoid the sick and the dying. And disruption of trade and communication was certain. Ever since the fourteenth century, the institution of quarantine has provided a feared yet politically compelling administrative option for communities during an epidemic. Even when—as has frequently been the case—physicians have questioned the contagiousness of a particular disease, most laymen have simply assumed that epidemic disease was almost by definition transmissible from person to person and have shunned those who might be potential sources of infection. In the United States, this pattern was regularly acted out during epidemics of yellow fever and cholera in the late eighteenth and early nineteenth century. Yet physicians then were often skeptical about contagion.[5]

In any severe epidemic, inexorably accumulating deaths and sicknesses have brought ultimate, if unwilling, recognition. If we were in fact writing the story of an epidemic in conventional dramatic form, that recognition might be an appropriate conclusion to a first act increasingly ominous in mood.

### *Act II. Managing Randomness*

Accepting the existence of an epidemic implies—in some sense demands—the creation of a framework within which its dismaying

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arbitrariness may be managed. Collective agreement on that explanatory framework may be seen as the inevitable second stage in any epidemic. For most previous centuries that framework was moral and transcendent; the epidemic had to be understood primarily in terms of man's relationship to God; consolation was grounded in submission to the meaning implicit in that framework. In plague-stricken London in the seventeenth century, for example, and eighteenth-century New England villages afflicted with diphtheria, most individuals construed an ongoing epidemic in just such otherworldly terms.[6] The sudden outbreaks of mortal illness were epiphenomena, forceful reminders of more fundamental realities. Since at least the sixteenth century, however, such spiritual assumptions have always coexisted with—and gradually yielded in emphasis to—more secular and mechanistic styles of explanation.[7]

Men and women have often expressed moral convictions as they have sought to explain and rationalize epidemics, but such values have ordinarily been articulated in terms of those mundane biological processes that ordinarily result in sickness or health. Individual and community sins could invite or prolong an epidemic—but only through the body's physiological mechanisms, not through miracles or God's direct interposition. This eclectic mixture of moral assumption and mechanistic pathology provided a style of explanation that has been fundamental to the social management of epidemics in the West for the past three centuries.

When threatened with an epidemic, most men and women seek rational understanding of the phenomenon in terms that promise control, often by minimizing their own sense of vulnerability. Not surprisingly, such consolatory schemes have always centered on explaining the differential susceptibility of particular individuals—on what was ordinarily termed predisposition in the eighteenth and nineteenth centuries, or what might be discussed today under the rubric of risk factors. How else explain why one person or class of persons succumbed while others did not? If susceptibility was not to be seen as a random accident or as the result of constitutional idiosyncracy alone, it had to be understood in terms of physiological mechanisms suggesting the physical—and risk-enhancing—effects of behavior, style of life, and environment. Such hypothetical schemes constituted a framework within which moral and social assumptions could be at once expressed and legitimated.

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Particularly important was belief in the connection of volition, responsibility, and susceptibility. During nineteenth-century cholera epidemics, for example, alcoholism, gluttony, sexual promiscuity, and filthy personal habits were widely accepted as predispositions to the disease. Such behaviors were seen as increasing susceptibility (and the likelihood of a poor outcome) even in smallpox, where contagion had been accepted for centuries.[8] It was hardly conceivable that such behaviors could be anything other than debilitating physically as well as morally; that an inveterate whiskey drinker might escape cholera by avoiding water could hardly have been accepted or understood. Bad was bad, culpable culpable, in every dimension of life. Even if one conceded that an epidemic might originate in some general environmental influence such as the atmosphere, selective susceptibility still demanded explanation. Everyone in a community breathed the same contaminated air; not everyone succumbed to the epidemic. Believers in contagion could entertain parallel views; infected individuals might encounter a good many men and women, only some of whom became ill.

Although such etiological views may in retrospect seem occasions for the expression of a crude and class-oriented moral hegemony, the eighteenth- and nineteenth-century debates about the cause of epidemics were in actuality rather more nuanced. Epidemics did tend, for example, to be associated with place of residence and occupation as well as behavior. And the environmentalist—and thus determinist and morally exculpating—implications were there to be drawn; people who worked overlong hours and lived in tenement apartments without adequate ventilation or access to water would necessarily be less able to fight off a disease.[9] The managing of response to epidemics could serve as a vehicle for social criticism as well as a rationale for social control. The same author might casually incorporate both elements; victims were predisposed by their environment to indulgence in such habits as drinking and sexual promiscuity yet could still be held responsible for the physical consequences of such indulgence. But this assumption hardly constituted a logical inconsistency for most individuals who thought about public health. Views in this field have always been murky and conflicting, and it is hardly surprising that such ambiguity should have been expressed during the course of past epidemics.

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For the poor and inarticulate, other mechanisms might be invoked to impose a certain order on an epidemic. Whether it was Jews poisoning wells, doctors seeking anatomical subjects, or the landlords and employers who forced them to live in unventilated hovels, poor people often found their own structure of blame—and meaning—in which to place an epidemic. The layman's almost universal association of epidemic with contagious disease played a parallel role. At least a presumed knowledge of the epidemic's mode of transmission could provide a measure of understanding and thus promise control.

*Act III. Negotiating Public Response*

Recognition implies collective action. One of the defining characteristics of an epidemic is in fact the pressure it generates for decisive and visible community response. The contrast with a disease such as tuberculosis is instructive; although far more significant demographically in the nineteenth century, tuberculosis did not elicit the sense of crisis that accompanied epidemics of yellow fever and cholera. Nor did it elicit moral and political pressure for immediate and decisive measures. In the stress of an epidemic, on the other hand, failure to take action constitutes action.[10] An epidemic might in this sense be likened to a trial, with policy choices constituting the possible verdicts.

This similarity suggests another dramaturgic aspect of an epidemic: measures to interdict an epidemic constitute rituals, collective rites integrating cognitive and emotional elements. In this sense the imposition of a quarantine, let us say, or the burning of tar to clear an infected atmosphere, the gathering of men and women in churches for days of fasting and prayer, all play a similar role—the visible acting out of community solidarity. At the same time, these collective rituals affirm belief—whether in religion, in rationalistic pathology, or in some combination of the two—while those beliefs promise a measure of control over an intractable reality. It is hardly surprising that communities should in moments of fear and incipient social disorganization seek the reassurance of familiar frames of explanation and logically consequent policies that provide both meaning and the promise of efficacy.

Since the eighteenth century, our rituals have been of a diverse sort. We have appealed in an eclectic way to a variety of sources of authority; days of prayer and fasting might be proclaimed along with

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the simultaneous enactment of procedures to cleanse and disinfect. For the historian and the social scientist, of course, the content of public rituals provides insight into social values at particular times, while conflicts over priorities among them provide insight into structures of authority and belief. Thus in the 1832 cholera epidemic, inconsistencies between lay and medical views of contagion shaped policy throughout Europe and North America; laypersons almost unanimously assumed the new disease to be contagious, while medical opinion was divided. In America, to cite another attitudinal variable, hostility toward immigrants and Roman Catholics played a significant role in shaping responses to the epidemic, while in England class hostility and endemic suspicion of medical men and their motives played a larger role in defining policy options.[11] Nevertheless, as I have argued elsewhere, the picture of a consistent if occasionally awkward coexistence between religious and rationalistic or mechanistic styles of thought was characteristic of mid-nineteenth-century Anglo-American society and sharply delineated in response to the cholera epidemic.

The adoption and administration of public-health measures inevitably reflect cultural attitudes. The poor and socially marginal, for example, have historically been labeled as the disproportionately likely victims of epidemic illness, and they have been traditionally the objects of public-health policy. Often, indeed, good empirical evidence has supported such assumptions; experience as well as ideology has enforced the association. Such views have manifested themselves in a variety of ways. Nineteenth-century quarantines and disinfection were, for example, imposed on the poor and their possessions, not on the wealthy—on the steerage, not the cabin-class, passenger—even after the germ theory was well established. Polio provides another pertinent example. In New York's 1916 epidemic, prophylactic measures were enforced in the dirty and densely populated immigrant slums, which in the past had bred typhoid and typhus—and not in the more prosperous, less crowded, and seemingly salubrious suburbs and middle-class areas that in fact produced so many of the cases.[12]

Epidemics ordinarily end with a whimper, not a bang. Susceptible individuals flee, die, or recover, and incidence of the disease gradually

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declines. It is a flat and ambiguous yet inevitable sequence for a last act.

But it also provides an implicit moral structure that can be imposed as an epilogue. How had the community and its members dealt with the epidemic's challenge? Not only during its reign but—most importantly—afterwards? Historians and policymakers concerned with epidemics tend to look backward and ask what "lasting impact" particular incidents have had and what "lessons" have been learned. Have the dead died in vain? Has a heedless society reverted to its accustomed ways of doing things as soon as denial became once more a plausible option? This implicit moral agenda has often accompanied—and in some cases no doubt motivated—the more self-conscious and pragmatic concern of scholars with the evolution of public-health policy, let us say, or the demographic transition.[13] Epidemics have always provided occasion for retrospective moral judgment.

## AIDS IN HISTORICAL PERSPECTIVE: REMEMBERING TO REMEMBER

Our experience with AIDS during the past decade has reminded us of some very traditional truths. Most strikingly, we seem not to have conquered infectious disease. Death is not associated exclusively with a particular—and advanced—age. AIDS has reminded us as well that managing death has been traditionally a central responsibility of the physician (though by no means of the physician alone). We have not, it seems, freed ourselves from the constraints and indeterminacy of living in a web of biological relationships—not all of which we can control or predict. Viruses, like bacteria, have for countless millennia shared our planet and our bodies. In some ways AIDS is a very traditional phenomenon indeed.

Nor have we revolutionized the framework within which we respond as a community to epidemic disease. In a good many ways the AIDS experience has reenacted the traditional dramaturgic structure of earlier epidemics. One, of course, is the gradual and grudging acceptance of the epidemic as reality—and the resentment expressed toward bringers of bad tidings, the physicians and activists who demand a response to this new threat.[14] Equally obvious is the way in which coping with randomness provides an occasion for reaf-

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firming the social values of the majority, for blaming victims. Framing and blaming are inextricably mingled; the details vary, but the end is similar. The peculiar mixture of biological mechanism invested with moral meaning is equally traditional.

Most Americans prefer to deal with a threat that they do not see as "meant" for them. The search for a reassuring connection of volition, behavior, and pathological consequence is as much alive today as it was in Philadelphia in 1793 and New York in 1832. Transgression implies punishment; affliction implies prior transgression. The historic circumstances and epidemiological peculiarities of AIDS have made such connections unavoidable in the public mind—and in their seemingly empirical character have obscured the social and psychological functions implicit in the underlining of that connection.

AIDS has reminded us as well of the apparently inevitable juxtaposition of suffering and death with a search for meaning that has always characterized epidemics. Meanings vary, but the need to impose them does not. Most Americans find reassurance in their accustomed faith in the laboratory and its products; they see AIDS as a time-bound artifact of that unfortunate but essentially transitional period between the discovery of this new ill and the announcement of its cure. Others, of course, see its primary meaning in the realm of morality and traditional piety. Many of us, of course, impose multiple frames of meaning on these biological events. The majority of Americans retain their faith in the laboratory but at the same time believe that AIDS points variously to truths about government, the political process, and personal morality.[15] The linked sequence of biological event and its moral management seems unavoidable.

But there is another aspect of public-health history that AIDS also recalls. For the sake of convenience diseases can be divided into two categories: diseases whose prevention demands individual behavioral change—like syphilis, AIDS, and lung cancer—and diseases that can be prevented by collective policy commitments—like typhoid fever, where the aggregated knowledge and decisions of bacteriologists, civil engineers, administrators, and elected officials have protected individuals whose habits need not have changed at all.[16] AIDS reminds us of the difficulty of inducing changes in behavior and thus of the intrinsic complexity of the decisions facing local governments and public-health authorities.[17]

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Contemporary sensitivity to individual rights only underlines the centrality of this dilemma, as does our novel public willingness to publicly discuss sexual behavior. Despite these characteristic aspects of today's social scene, parallels with earlier health campaigns are obvious. During the first decades of this century, for example, public-health workers who urged the use of condoms and prophylactic kits to prevent syphilis met some of the same kind of opposition their successors in the 1980s faced when they advocated distributing sterile needles to intravenous drug users. In both cases ultimate values came into conflict. In both cases debate turned on distinctions between "deserving" and "innocent" victims—in the case of syphilis, the presumed innocents being the wives of erring husbands and their infants; in the case of AIDS, the recipients of contaminated blood or the offspring of infected mothers.[18]

These cases remind us as well of the need for ritual, even in a fragmented modern society. It is a need that is recognized in the AIDS memorial patchwork quilt that has recently circulated throughout the United States; it is recognized, I suggest, even in the whimsically self-conscious and public distribution of condoms on college campuses and in other public spaces; it is recognized in the calling of conferences graced by individuals representing various agencies of social authority—scientists, administrators, even the odd historian. Each ritual implies collective responsibility and communal identity. Each invokes a differentially nuanced frame of meaning—in the case of the quilt, a commitment to egalitarian compassion; in the distribution of condoms, a commitment to the potential of applied science. If science and technology allow us to control and predict, it is a realm of value worth invoking collectively.

## AIDS, A MODERN EPIDEMIC

In a number of obvious ways, however, AIDS does not fit easily into the traditional pattern I have outlined. One, for example, is the rapidity of its geographic spread and the parallel rapidity of its identification as a unified clinical entity.[19] It might well be described as modern, and even postmodern, in its relationship to scientific medicine and institutional structures. AIDS is postmodern in the self-conscious, reflexive, and bureaucratically structured detachment with which we regard it. Countless social scientists and journalists

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watch us watch ourselves; that reflexive process has become a characteristic aspect of America's experience with AIDS.

More generally the epidemic has existed at several levels simultaneously, mediated by the at first uninterested, then erratically attentive media. For most Americans—insofar as this epidemic can be construed as a national phenomenon—it is a media reality, both exaggerated and diminished as it is articulated in forms suitable for mass consumption. The great majority of Americans have been spectators, *in* but not *of* the epidemic.

Another significant difference between this and earlier epidemics grows out of the novel capacities of late twentieth-century medicine. Without its intellectual tools, the epidemic would not have been understood as an epidemic; we could not easily have determined that it is a clinical entity with protean manifestations. Providing substantive cognitive change during the course of an ongoing epidemic, the laboratory and its intellectual products have played a novel role in the narrative structure of our encounter with AIDS. Without the option of serological screening, for example, the intense and multifaceted debate over the imposition of such tests could hardly have been framed. Without knowledge of an infectious agent, the options for public policy would necessarily have been defined differently.

Another modern characteristic of America's experience with AIDS mirrors the institutional complexity of our society. That structured complexity has in scores of ways shaped responses to this crisis. (Response to epidemics has, of course, always been constrained by preexisting institutional forms and prevailing values, but twentieth-century institutional structures seem categorically different—if only in scale.)

Institutional complexity implies institutional interest—and thus conflict. Certainly we have seen this in the case of AIDS. Blood banks, hospitals, the National Institutes of Health and its several components, and state and municipal departments of public health have all played particular yet necessarily linked and interactive parts. Similarly, the not always consistent interests of local and national government, and of political parties, have also helped shape the nature and pace of our society's response to AIDS. Even patients and their advocates have become public activists in a generation newly conscious of individual and group rights. Perhaps least surprising is the way in which our courts have provided a mechanism for resolving

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the difficult policy choices posed by AIDS. As we are aware, American courts have become the residuary legatee of a variety of intractable social problems. Recently, a judge in Florida, for instance, decided that a child with AIDS should not be excluded from the classroom—but would have to remain within a glass-enclosed cubicle while in attendance.[20] As in many other instances in our society, conflicting attitudes and interests find their way into courts where judges and juries must of necessity make *ad hoc* decisions.

Finally, Americans have created a complex and not always consistent health-care system, and AIDS has been refracted through the needs, assumptions, and procedures of that system. The epidemic might be seen as a socio-assay of that system. Just as costs have been problematic in the system, so have they in the case of AIDS. AIDS has, in particular, forcefully reminded us of the difficulty of providing adequate care for the chronically ill in a system oriented disproportionately toward acute intervention—and of the complex linkages between disease categories, hospital policies, and reimbursment formulas. In this sense, AIDS might be seen as an exacerbation of a chronic pathology.[21]

The gap between isolating an infectious agent in a laboratory in Paris or Bethesda and the imposition of a preventive program altering the behavior of particular people in particular places is difficult and problematic. But this is no more than characteristic; clinical application does not follow inevitably from technical consensus. AIDS provides a powerful *de facto* argument for an integrated system-oriented approach to public health and health care; neither the laboratory's contributions nor the social contexts in which that knowledge is employed can be seen in isolation.[22]

### *AIDS as a Postmodern Epidemic*

The role of the media and social scientists in our contemplating ourselves is obvious enough, but AIDS can be seen as postmodern in several other ways as well. Perhaps most strikingly, it is a postrelativist phenomenon.[23] After a generation of epistemological—and political—questioning of the legitimacy of many disease categories, AIDS has underlined the inadequacy of any one-dimensional approach to disease, either the social constructionist or the more conventional mechanistically oriented perspective. AIDS is socially constructed (as society perceives and frames the phenomenon, blames

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victims, and laboriously negotiates response) yet at the same time fits nicely into a one-dimensionally reductionist and biologically based model of disease. AIDS can hardly be dismissed as an exercise in victim blaming, even if it is an occasion for it. It is no mere text, words arranged to mirror and legitimate particular social relationships and perceptions. On the other hand, we can no longer remain unaware that biopathological phenomena are framed and filtered through such agreed-on texts.

Of course, a good many Americans never succumbed to the relativist mood of the late 1960s and 1970s, while others have always regarded the social claims of medicine with skepticism, even if they did not question the legitimacy of its disease categories. Others of us have tried to steer a more tentative course. We live in a fragmented society, and not even the most myopic cultural anthropologist would find it easy to impose a neatly coherent and unified cultural vision on the diverse group of individuals who inhabit the continental United States.

Yet AIDS has reminded us that we all share at least some common fears and ways of responding to social crisis. "They fancied themselves free," as Camus wrote of the citizens of the soon-to-be plague-stricken Oran, "and no one will ever be free so long as there are pestilences." At the end of his narrative, Camus's physician-narrator reflects, even as he listens to the cries of joy that greet the opening of the city and the official conclusion of the epidemic, ". . . that perhaps the day would come when, for the bane and the enlightening of men, it would rouse up its rats again and send them forth to die in a happy city."[24] Plague reminds us that human beings will not so easily escape the immanence of evil and the anxiety of indeterminacy. Mortality is built into our bodies, into our modes of behavior, and into our place in the planet's ecology. Like other epidemics, AIDS has served well to remind us, finally, of these ultimate realities.

ENDNOTES

[1]These are endemic phenomena, and a fundamental aspect of the root meaning of *epidemic* lies precisely in its contrast with such "domesticated" phenomena. The *Oxford English Dictionary* tells us that when referring to a disease, the term *epidemic* denotes "prevalent among a people or a community at a special time,

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and produced by some special causes and generally present in the affected locality." Epidemics have a unity of place as well as time—and even worldwide epidemics are experienced and responded to at the local level as a series of discrete incidents. In addition to fellow authors in this issue of *Dædalus*, I should like to thank Drew Gilpin Faust, Chris Feudtner, Renée Fox, Elizabeth Long, Harry Marks, and Rosemary Stevens for helpful comments on an earlier draft of this essay.

[2]Albert Camus, *The Plague*, trans. Stuart Gilbert (New York: Alfred A. Knopf, 1952), 7.

[3]There is an important parallel, moreover, between the biologically determined chronology of an epidemic and its social chronology. I refer, on the one hand, to the increasingly steep curve of case incidence, the exhaustion of susceptible individuals, and the gradual decline in mortality and morbidity and, on the other, to the social pattern of gradual recognition, negotiated response, and gradual decline.

[4]One might contend that there is a prior first act, or prologue, at the biological level. In the case of plague, this would have been acted out in the linked relationship among rats, fleas, and bacteria. The existence of these events prior to man's awareness of them communicates the chastening moral message that humankind exists in an intricate web of biological relationships. In periods with well-developed channels of communication such as the nineteenth century, another sort of prologue takes place "offstage," as particular communities follow the gradual spread of a pandemic and anticipate its arrival.

[5]On the vexing question of contagion in these ills, see E. H. Ackerknecht, "Anticontagionism between 1821 and 1867," *Bulletin of the History of Medicine* 22 (1948), 562–93; J. H. Powell, *Bring Out Your Dead, The Great Plague of Yellow Fever in Philadelphia in 1793* (Philadelphia: University of Pennsylvania Press, 1949); Margaret Pelling, *Cholera, Fever and English Medicine 1825–1865* (Oxford: Oxford University Press, 1978); Charles Rosenberg, "The Cause of Cholera: Aspects of Etiological Thought in Nineteenth-Century America," *Bulletin of the History of Medicine* 34 (1960): 331–354; William Coleman, *Yellow Fever in the North, The Methods of Early Epidemiology* (Madison: University of Wisconsin Press, 1987).

[6]Ernest Caulfield, *A True History of the Terrible Epidemic Vulgarly Called the Throat Distemper Which Occurred in His Majesty's New England Colonies between the Years 1735 and 1740* (New Haven: Yale Journal of Biology and Medicine, 1939).

[7]See for example, the present author's *The Cholera Years, The United States in 1832, 1849, and 1866* (Chicago: University of Chicago Press, 1962, new ed. 1987), which sought to trace that growing secularism.

[8]After the adoption of inoculation for smallpox in the eighteenth-century West, few physicians or laymen doubted that this endemic and often fatal disease was transmitted from person to person. Contagion was also assumed in venereal disease. In this instance, the connection between willed behavior and the incidence of disease was obvious.

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[9]The environmentalist emphasis fundamental to anticontagionist views of yellow fever and cholera provided a natural rationale for critical attitudes toward inattentive local government and exploitative landlords and employers.

[10]The action need not be efficacious by late twentieth-century standards but does imply a choice among intellectually and institutionally available options. In 1832, for example, American assumptions of inherently limited federal power meant that a truly national quarantine against the threatened importation of cholera was not a real option, while municipal and state quarantines were.

[11]See, for example, R. J. Morris, *Cholera 1832, The Social Response to an Epidemic* (New York: Holmes & Meier, 1976) and Ruth Richardson, *Death, Dissection and the Destitute* (London and New York: Routledge & Kegan Paul, 1987), 223–28.

[12]New York City Department of Health, *A Monograph on the Epidemic of Poliomyelitis (Infantile Paralysis) in New York City in 1916* (New York: New York City Department of Health, 1917); Naomi Rogers, "Screen the Baby, Swat the Fly: Polio in the Northeastern United States, 1916" (doctoral dissertation, University of Pennsylvania, 1986). In the 1920s and 1930s, on the other hand, a rather different social picture was created; polio-stricken children were romanticized.

[13]For a recent attempt to evaluate studies of cholera's social and institutional impact, see Richard J. Evans, "Epidemics and Revolutions: Cholera in Nineteenth-Century Europe," *Past & Present*, no. 120 (1988), 123–46.

[14]One might also note the desire to specify implausibly explicit beginnings—and clothe them with moral meaning. Compare the expository and narrative function of Camus's rat with the role played by Gaetan Dugas, the antisocial and hypersexual airline steward of Randy Shilts's recent best-seller *And the Band Played On: Politics, People, and the AIDS Epidemic* (New York: St. Martin's Press, 1987). A rodent vector obviously provides the occasion for a rather differently nuanced moral agenda. One can hardly blame a rat.

[15]Even scientists can, and doubtless do, understand seemingly objective statements at several levels simultaneously. "When certain immunologists suggest that predisposition to AIDS may grow out of successive onslaughts on the immune system—it may or may not prove to be an accurate description of the natural world. But to many ordinary Americans (and perhaps a good many medical scientists as well) the meaning lies in another frame of reference. . . . the emphasis on repeated infections explains how an individual had predisposed him or herself. The meaning lies in behavior uncontrolled." And suitably punished. See Charles E. Rosenberg, "Disease and Social Order in America: Perceptions and Expectations," *Milbank Quarterly* 64 (suppl. 1) (1986):52.

[16]The spread of AIDS through the blood-banking and processing system represents an instance of this category of intervention—one in which the transmission of a disease can be limited or halted without inducing behavioral change in prospective victims.

[17]The layman's persistent belief in contagion through casual contact despite the reassuring words of medical authority reenacts another traditional element in the history of epidemic disease.

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[18]Compare Allan M. Brandt, *No Magic Bullet, A Social History of Venereal Disease in the United States since 1880, with a New Chapter on AIDS* (New York: Oxford University Press, 1987). On "syphilis of the innocent," see L. Duncan Bulkley, *Syphilis in the Innocent . . . Clinically and Historically Considered, with a Plan for the Legal Control of the Disease* (New York: Bailey & Fairchild, 1894). There are a good many other parallels between AIDS and syphilis, such as the proposed criminalization of the knowing transmission of the disease. Changed attitudes toward female sexuality have, however, altered presumptions of female "innocence" and responsibility.

[19]The contrast with the very gradual elucidation of such protean clinical entities as syphilis, tuberculosis, and rheumatic fever is instructive. Although AIDS may seem to have appeared suddenly in the public consciousness, as a biological phenomenon it has been extremely slow in developing, certainly in comparison with other virus diseases such as measles and influenza.

[20]*New York Times*, 23 August 1988, A14.

[21]And, needless to say, it underlines as well the often less than adequate preparation of medical personnel for dealing with fatal illness. That AIDS is infectious as well as almost invariably fatal provides an exacerbating element that differentiates it from the great majority of chronic life-threatening ills.

[22]The epidemic has illustrated the geographical integration of society as well; AIDS has made clear North America's relationship with other countries and continents. Our traditional habit of largely ignoring African health conditions may be a luxury we can no longer afford.

[23]Rosenberg, 35–6, 53.

[24]Camus, 35, 278.

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*Margaret A. Hamburg, M.D., and*
*Anthony S. Fauci, M.D.*

# AIDS: The Challenge to Biomedical Research

THE SUDDEN, UNEXPECTED EMERGENCE of the acquired immunodeficiency syndrome (AIDS) has become the focus of extraordinary attention and concern. First recognized as an entity less than eight years ago, this infectious, debilitating, and ultimately lethal disease represents the most severe stage of a spectrum of infection with the human immunodeficiency virus (HIV). It has appeared, in epidemic proportions, in an era when advances in medicine and public health have fostered great confidence in the ability of biomedical science to conquer disease. The prematurely complacent belief that infectious diseases would no longer threaten the developed world has been abruptly and definitively shattered by the onset of AIDS.

As of December 1988, the United States has had more than 81,000 documented cases of AIDS and close to 46,000 deaths from the disease.[1] In the United States, 1 million to 1.5 million individuals are thought to be infected with HIV but have not yet developed clinical symptoms.[2] In the entire world, current estimates indicate that there are presently more than 250,000 cases of AIDS and somewhere between 5 million and 10 million individuals infected with HIV.[3] It

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is even more sobering to examine projections for the future. Accounting for both the rates of progression from infection to disease and the rates of new infection, the United States Public Health Service estimates that by the end of 1992, this country will have had a total of approximately 365,000 cases of AIDS and close to 263,000 AIDS deaths. In 1992 alone, it is projected that there will be 80,000 new cases of AIDS diagnosed in this country—nearly as many cases in one year as have occurred in our entire experience with the disease to date.[4]

As the number of reported cases of AIDS mounts, the magnitude and severity of the problem becomes increasingly evident, and the urgency of developing effective strategies to prevent and control HIV infection more pronounced. From a scientific perspective, progress in understanding this disease process has moved forward at an impressive rate. Since the initial descriptions of the syndrome in the early 1980s, the fundamental manifestations of the disease have been documented and the general contours of the epidemic delineated. Basic research efforts have led to the discovery of the causative agent (HIV), the development of a blood test for the virus, as well as insight into the targets for the virus in the body, the body's responses to infection with the virus, and the pathogenic mechanisms whereby the virus produces its deadly effects. In recent years, a nationwide clinical trials program has been established to test experimental AIDS therapies, and several trials of AIDS vaccine candidates are currently under way.

Yet despite these advances, no definitive cure or effective vaccine is yet available, and the toll of the epidemic continues to rise. The more knowledge is accumulated about the virus and the disease it produces, the more complex the picture becomes. In this article we shall attempt to outline the important accomplishments and the current status of basic and clinical AIDS research efforts and to identify certain of the promising new avenues for scientific pursuit, as well as obstacles to progress and some of the special problems that have arisen.

## THE INITIAL CHALLENGE: THE SEARCH FOR A CAUSE

In the late 1970s, a rare type of cancer and a variety of serious infections were recognized to occur in increasing numbers of previously healthy young men who resided predominantly in New York

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and California. Most of this initial group of patients had Kaposi's sarcoma, an unusual skin tumor generally not seen in this age group, or *Pneumocystis carinii* pneumonia, a rare lung infection that virtually never occurs in individuals with normal immune function.[5] First formally described in 1981 as a disease affecting homosexual and bisexual men, AIDS was later reported in intravenous drug users, hemophiliacs, and recipients of blood transfusions. It was also noted that the sexual partners of AIDS patients could contract the disease.[6]

Despite the lack of an established cause for AIDS at this time, efforts to respond to the challenge of this new disease process were vigorous and drew upon many disciplines. Review of the medical literature, autopsy records, and tumor registries revealed no precedent for the striking new incidence of such cases. Epidemiologic studies in the United States and abroad were initially undertaken to define the affected populations and to search for clues to the cause of the disease. Such research activities, along with natural-history studies of the disease, provided important insights into modes of transmission, patterns of disease occurrence and progression, as well as possible cofactors.

Immunologic evaluation of AIDS patients revealed severe defects in their immune systems, making them susceptible to unusual cancers and so-called opportunistic infections, which a normal immune system would protect against. The damage to the immune system was observed to result predominantly from the selective depletion of a certain subset of white blood cells referred to as T4 lymphocytes.[7] These T4 lymphocytes play a critical role in orchestrating the entire immune system and are essential to the body's defense mechanisms. It was presumed that the immune defect in these patients was acquired, but the mode of acquisition was undetermined.

In 1983, a previously undescribed T-lymphotropic virus was concurrently isolated from AIDS patients by Dr. Robert Gallo at the National Institutes of Health and by Dr. Luc Montagnier at the Pasteur Institute in Paris. Early on, the virus was multiply designated as human lymphotropic virus (HTLV) III, lymphadenopathy-associated virus (LAV), and AIDS-associated retrovirus (ARV).[8] Now officially called the human immunodeficiency virus (HIV), considerable evidence demonstrates that this organism, an RNA retrovirus belonging to the lentivirus family, is the causative agent of AIDS. Little is known with certainty about the biologic and geo-

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graphic origins of this virus, but this would appear to be the first time in recorded history that it has spread widely in the human population. Related viruses have been observed in animal populations but do not produce disease in humans. A distinct but related virus (HIV-2) does cause disease in humans, and it is now being actively studied.[9]

## RESEARCH ON HIV INFECTION AND AIDS

The initial recognition of AIDS as a distinct entity created the need for intensive scientific study directed at this new disease. Truly rapid advances have been achieved, due in large part to the extraordinary foundation in basic science research developed over the past few decades. The remarkable expansion of knowledge in the areas of immunology, virology, microbiology, molecular biology, and drug and vaccine development have enabled AIDS scientists to proceed in a rational and expeditious manner.

Broadly viewed, biomedical research on HIV infection and AIDS can be divided into five major scientific categories: (1) the study of the distribution of HIV infection and AIDS in the population (epidemiology) and the pattern of disease progression (natural history); (2) the identification and characterization of the virus that causes AIDS (the etiologic agent); (3) delineation of the mechanisms by which the virus destroys the immune system and produces disease (pathogenesis); (4) the development and testing of potential therapies for HIV infection and its complications; and (5) the development and evaluation of potential AIDS vaccines.

### *Modes of Transmission and the Epidemiology of Infection*

The routes of HIV infection have been studied extensively. Researchers have isolated HIV from a number of body fluids, including blood, semen, saliva, tears, urine, cerebrospinal fluid, breast milk, and cervical and vaginal secretions. However, epidemiologic evidence strongly indicates that HIV is transmitted through only three primary routes: sexual contact (including anal and vaginal intercourse) with an infected person, exposure to infected blood or blood products, and passage from an infected mother to her infant before or during birth.[10]

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Current U.S. statistics reveal that the majority of sexual transmissions of HIV have occurred between homosexual or bisexual men, representing approximately 62 percent of all AIDS cases. Exposure to HIV-infected blood through the sharing of needles or other drug-related paraphernalia is another source of HIV infection, and intravenous drug abusers comprise approximately 20 percent of the present cases of AIDS. An additional 7 percent of HIV cases occur among individuals who are both homosexual and intravenous drug abusers. Heterosexual HIV transmission in the United States accounts for roughly 4 percent of all reported AIDS cases. About 3 percent of the AIDS cases occurred through transfusion of infected blood or blood products, although the current practice of screening blood donors and testing all donated blood and plasma for HIV antibodies has virtually eliminated this route of transmission.[11] HIV transmission in breast milk is an extremely uncommon mode of spread, although it has been sporadically reported.[12] There is no scientific evidence to support the idea that the virus is transmitted through ordinary nonsexual contact.[13] Claims that HIV can be transmitted by insect transmission have been repudiated by both laboratory and epidemiologic studies.[14]

Careful, ongoing epidemiologic surveillance studies are essential to monitoring levels of HIV infection and trends in new infection among groups recognized to be at increased risk (such as homosexual males and intravenous drug abusers), various demographic subgroups (based on sex, age, and race or ethnic group), and the general population. Considerably more needs to be learned about the contributing factors and quantitative risks of HIV infection through various transmission modes, including type of sexual contact, mother-to-infant transmission, patterns of intravenous drug abuse, receipt of blood or blood products, and occupational exposures to blood or infected fluids. Such data are of critical importance to assessing the mechanisms of transmissibility of the virus, its biologic determinants, and/or the cofactors influencing individual susceptibility to infection. Both the biomedical and the public-health implications of such information are enormous.

Following infection with HIV, a person may experience an acute, transient, mononucleosis-like febrile illness but generally remains virtually asymptomatic for several years before progressive immunologic deterioration results in the opportunistic infections or cancers

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that characterize the diagnosis of AIDS.[15] The period between initial infection with HIV and the development of AIDS can be quite variable. Recent data indicate that 15 percent to 46 percent of HIV-infected individuals will develop AIDS within seven years of infection.[16] Over the longer term, statistics on HIV disease progression remain to be determined, but many scientists fear that in the absence of the discovery of effective therapeutic interventions, virtually 100 percent of those infected with the virus will eventually develop acute AIDS. Furthermore, although asymptomatic HIV-infected individuals may appear healthy, a growing body of evidence suggests that they progressively experience subtle but important subclinical defects of immune function.

There is increasing recognition that the clinical syndrome of AIDS represents the terminal stage of a spectrum of HIV infection. Once the diagnosis of AIDS is made, the clinical course generally follows a relentless decline, with death occurring within one or two years. However, earlier diagnosis, the development of the antiviral agent Zidovudine (AZT), and improvements in the treatment of the complications of HIV infection are leading to prolonged survival for persons with AIDS.[17]

In addition, intensive research efforts are being focused now on the critical period between initial infection and the fully developed disease. New insights may enable early interventions to arrest or slow progression of HIV infection prior to the development of AIDS.

### *The Nature of the Virus*

Following identification of the causative agent of AIDS (HIV-1), intensive efforts to investigate the nature of the virus, its functions, and its effect on human cells began. Knowledge has accumulated at a pace unprecedented for research on disease-causing microorganisms.

As seen through an electron microscope, the HIV RNA retrovirus appears as a dense cylindrical core encasing two molecules of the viral genome (genetic material). A spherical outer envelope surrounds the central core.[18] The genetic material of the virus has been cloned and sequenced and its precise structure delineated. For the most part, the specific functions of the viral genes as well as the functions of the proteins encoded by those genes have been identified and studied.[19] Such understandings serve as the basis for many important AIDS

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research endeavors, including attempts on a molecular level to interfere with specific functions of the virus and to influence infectivity by manipulating specific components of the virus. Scientists are also using information about the nature and function of the HIV genome to provide a framework for the development of potential AIDS vaccines and to attempt to develop antiretroviral drugs in a targeted fashion designed to interfere with the ability of the virus to replicate itself or cause infection. In addition, isolation of the virus has made possible the development of HIV blood-screening tests. This has important public-health applications for safeguarding the blood supply, as well as for diagnostic and surveillance purposes.

Significant progress has also been made in understanding the life cycle of the virus. Similar to other viruses, HIV cannot reproduce without taking over the biosynthetic machinery of the host cell. Like all retroviruses, HIV possesses a special enzyme, reverse transcriptase, which is capable of making a DNA copy of the viral RNA. This enables the virus to reverse the normal flow of genetic information from RNA to DNA (referred to as proviral DNA), which is then incorporated or integrated into the genetic material of the host. Once integrated, the virus can remain in a latent state for a variable, often lengthy, period until activated.[20]

That HIV is a retrovirus, with this unique ability to insert its genes into the genetic machinery of the host cell, greatly complicates the task of developing effective therapies and vaccines. HIV can remain dormant or latent, shielded from either pharmacologic or immunologic attack. While developing therapies for viral diseases has always been problematic, devising an antiretroviral therapy may prove even more difficult.

Nonetheless, the HIV replicative cycle offers several opportunities for effective intervention. One area of investigation concerns the critical step in HIV infection whereby the virus binds to a host cell receptor to gain entrance to the cell. It has been demonstrated that a molecule called CD4—expressed predominantly on the surface of T4 lymphocytes—serves as a receptor for HIV.[21] Thus, the T4 cell represents a major target for HIV infection; however, other cells expressing the CD4 surface molecule are capable of binding and becoming infected with HIV. Various mechanisms have been proposed to interfere with this process of virus-receptor binding and entrance into host cells. Several are under active study.[22] Another

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area of investigation involves interfering with the activity of the enzyme reverse transcriptase, thereby disrupting a crucial initial step in the replicative cycle of the virus. Other potential targets of vulnerability of the virus include interference with proviral DNA transcription (the process by which genetic information contained in DNA is translated into an RNA message), disruption of the subsequent protein synthesis, processing, and assembly and the final stage of viral replication in which mature virions bud off from host cells.[23]

*The Attack on the Immune System*

HIV infection can result in a wide range of immunologic and clinical abnormalities. Although multiple components of the immune system are at least indirectly affected in individuals with HIV infection, it is the impairment of the responses mediated by the class of lymphocytes called T4 cells that appears to produce the most significant clinical consequences.[24] Because the T4 cell is pivotally involved in virtually all immune responses, a major host defense defect results from T4-cell depletion and renders the body highly susceptible to opportunistic infections and neoplasms. It has recently been demonstrated that certain other types of white blood cells called monocytes and macrophages, including bone marrow precursor cells, can be infected without marked cell damage.[25] The monocyte, which moves relatively freely throughout the body, may serve as a reservoir for HIV and may play a significant role in the propagation of HIV infection and the development of AIDS. It is now well established that the brain is also a target for HIV.[26] Present evidence suggests that many of the central nervous system manifestations of HIV are produced by infected monocytes that travel into the brain and indirectly damage neuronal tissue. Research reveals no evidence to support direct infection of nerve cells by HIV.

The development of a new technique called polymerase chain reaction (PCR) will greatly enhance the ability of scientists to detect the presence of HIV genetic material in cells. This technique involves selective DNA amplification and makes it possible to multiply otherwise undetectable fragments of DNA. Using PCR, it is possible to determine the presence of HIV viral genes in blood samples in which as few as 1 in 1 million lymphocytes is infected.[27] The

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expanding use of PCR in AIDS research will result in important new insights into the nature and extent of HIV infection.

Considerable progress has been made in understanding the pathogenic mechanisms of HIV infection, including the receptor whereby the virus gains entry into the cell and the subsequent intracellular events of the virus life cycle and replication. The disease complications that result from the virus-induced destruction of immune cells have also been fairly extensively delineated. Nonetheless, some of the most basic mechanisms by which HIV exerts its lethal effects on host immune cells remain unknown. In test-tube experiments, HIV can be demonstrated to rapidly kill the cells it infects. It is not clear, however, that such a phenomenon can fully explain the profound depletion of T4 cells observed in patients with AIDS, since only a small percentage of the T4 cells in the peripheral blood (perhaps less than 1 in 10,000) is found to express the virus at any given time. Several proposed explanations for this apparent discrepancy are currently being explored.[28] A better understanding of the process of cell destruction by HIV will therefore be important to the development of effective interventions.

Because the clinical syndrome of AIDS follows infection with HIV after a variable, often long, period, there is a pressing need to learn more about this interval between initial infection and acute disease. It may well be that our best prospects for treatment and control of HIV disease will come through interventions during this critical time. Toward this end, intensive efforts must be directed toward unraveling the mechanisms of immune-system dysfunction and the factors that influence or control disease progression.

Laboratory experiments have demonstrated that when certain cells are infected with HIV, latent infection may ensue, with the viral DNA becoming integrated into the DNA of the host cell without virus production.[29] In addition, infection may be chronic in a given cell with a low level of virus production or expression. A variety of activation signals, including other viruses as well as substances produced by immune-competent cells following stimulation, appear to contribute to the conversion of a latent or a chronic infection to a productive one.[30] Modification of these activation signals—either pharmacologic or otherwise—may have important implications for

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potential strategies to limit the progression of HIV infection and of AIDS.

*The Search for a Treatment*

Researchers are in the midst of a major effort to discover, develop, and test potential therapies for HIV infection and AIDS. These efforts have focused on two major areas: (1) antiviral drugs with a direct effect against the causative agent, HIV, and (2) immunomodulators that act to reconstitute or enhance immune-system function in patients with HIV infection and AIDS. Efforts to develop and improve approaches to treat the specific opportunistic infections and cancers associated with AIDS are also moving forward.

The successful development of antiviral and/or immune enhancement therapy represents a challenge of enormous magnitude. Basic scientific understandings must obviously underlie the process of rational development of therapeutic agents. Unlike any other known pathogen, HIV infects the very cells of the immune system that are intended to direct the immune system's attack against such invaders. In addition, because the virus becomes intimately associated with the host cells during the course of its life cycle, the task of finding a safe and effective therapeutic agent is even more formidable. It will be necessary to discover a means to interrupt the life cycle of the virus within the cells it invades without killing the cells themselves and destroying the already threatened immune system. Also, cell-free viruses must be eliminated, and the spread of the virus to uninfected cells prevented. Furthermore, recent studies indicate that there may be several important reservoirs for HIV in the body that will be difficult to eliminate without causing fundamental damage to the host cells involved. For example, cells of the monocyte-macrophage line, important components of the immune system, can not only be infected but can also support HIV replication while harboring the virus from the body's immune surveillance. Circulating monocytes and macrophages appear to play an important role in the dissemination of HIV throughout the body, including the brain.[31] Recent studies suggest that bone-marrow precursor cells of monocyte lineage may be an additional reservoir of HIV.[32] In the search for effective therapy, due consideration must be given to ensuring that the agent(s) can penetrate into the involved sites. For example, as the brain is an important target for HIV infection, any effective anti-HIV agent

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should be able to cross the blood-brain barrier. Other practical considerations in AIDS drug development must include cost, dosing schedule, and the route of administration.

*Preclinical Drug Development*—Researchers attempting to discover and develop anti-HIV drugs are pursuing two approaches: screening large numbers of existing compounds for activity against HIV and targeting drug development with information gained about unique properties and critical functions of the virus to design agents that interfere with structural components or the life cycle of the virus.

To date, literally thousands of compounds have been studied in the test tube for activity against HIV. Of these, several have been identified to show significant anti-HIV activity and have advanced to clinical trials in humans.[33] Nonetheless, there is fairly broad scientific consensus that definitive therapies for HIV infection will derive from precise, targeted drug development based on intimate knowledge of the virus, its life cycle, and the delineation of specific sites and mechanisms for disrupting viral replication or viability. This may be a painstaking and difficult process, requiring the talents of virologists, molecular biologists, pharmacologists, physical chemists, and crystallographers, among others, and may take years to show results.

*Clinical Trials of Experimental Drugs*—Clinical trials are designed to investigate the beneficial and adverse effects of drugs that show promise in the laboratory or in preliminary clinical studies. Because of the experimental nature of such potential therapies, it is essential that they be carefully and scientifically studied for safety and efficacy before being widely distributed. Many clinical research efforts are under way, including a major, nationwide clinical trials network established by the National Institutes of Health (NIH) to study potential antiretroviral and immunomodulatory treatment approaches in persons infected with HIV, as well as specific therapies (including prophylaxis) for the opportunistic infections and malignancies associated with HIV infection.

At the present time, AZT, a compound that interferes with virus replication, is the only drug licensed by the Food and Drug Administration (FDA) for the treatment of HIV infection. Its potential use as a therapeutic agent against HIV was originally demonstrated in the test tube by the screening procedure mentioned above. Carefully conducted clinical trials subsequently demonstrated that AZT admin-

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istration could significantly prolong life for certain individuals with AIDS, although its use can be associated with considerable toxic side effects, including bone-marrow suppression.[34] A number of related antiviral compounds are being investigated now to see if they might be equally effective with fewer side effects. Other drugs, both alone and in combination with lower doses of AZT, are also being tried in the hope of achieving greater benefit with reduced toxicities.

In many ways, combination therapy represents the most promising new approach to the treatment of HIV infection. For example, the agent 2′,3′-dideoxycytidine (ddC) has good antiviral activity without AZT's marrow-suppressive effects, but it has the dose-limiting toxicity of producing what is called a peripheral neuropathy with severe, damaging pain in the feet. By alternating AZT treatment with ddC, patients may be able to receive therapy for longer periods of time, at higher doses, and with fewer side effects. Similarly, bone-marrow suppression might be lessened through the combination of drugs like AZT with compounds that can boost blood-cell counts, such as erythropoeitin or granulocyte-macrophage-colony-stimulating factor (GM-CSF). Another intriguing approach involves combining antiviral therapy with immunologic reconstitution, either with biological response modifiers that can boost immune response such as alpha-interferon and interleukin-2 or through bone-marrow transplantation techniques.[35] This approach provides a potential two-pronged attack aimed at suppressing viral replication at the same time that the damaged immune system is restored.

Several drugs have shown evidence of therapeutic value against the major opportunistic illnesses seen in AIDS. Important examples include the use of aerosolized pentamidine to prevent *Pneumocystis carinii* pneumonia (the leading cause of death among AIDS patients), as well as the use of the antiviral drugs foscarnet and ganciclovir (DHPG) in controlling the progression of cytomegalovirus retinitis. Studies of these and other potential therapies are currently under way to evaluate definitively their safety and efficacy. Altogether, dozens of agents for use in HIV infection and AIDS are currently being tested in clinical trials in this country and around the world.

There is a growing emphasis on exploring means for early therapeutic intervention in HIV infection in order to limit or prevent progression to full-blown AIDS. A number of important studies are near implementation or are already under way to examine the

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influence of experimental therapies in early stages of the disease, in infected but asymptomatic individuals, and even in pregnant women who are HIV-infected (so as to prevent infection in the fetus). Considerable attention is also being directed at finding treatments that will prevent the onset of certain opportunistic complications of HIV disease.

The advances currently being made in drug discovery, development, and therapeutic intervention provide a basis for cautious optimism that a number of useful agents may be available relatively soon. Realistically, there may never be an absolute cure for AIDS. At least for the next few years, it is likely that the best hopes for treatment will come from drugs or combinations of drugs that will permit sufficient control of the infection so that HIV-infected individuals can live healthier lives with a reasonable life span and no longer infect others.

*Need for Continued Commitment to Scientific Basis for Clinical Trials*—Given the life-threatening nature of HIV infection and AIDS, there is a growing tension between the understandable desire to make potential therapies available as quickly and as widely as possible, and the need to obtain correct and enduring answers through carefully designed scientific research.

Concern has been expressed that scientists are rigidly adhering to experimental traditions that are not relevant to the AIDS crisis and that impede progress to solutions. In view of the lethal threat posed by the underlying disease, the very rationale for conducting methodical, controlled clinical trials of experimental AIDS therapies has been called into question; many believe that experimental clinical drug protocols are too complex, take too long to develop, and once developed are too restrictive in their criteria for admission and execution. Correspondingly, there is strong pressure on the scientific community to loosen the standard practices used for evaluating drugs and to abandon the need to scientifically prove both safety and efficacy. Yet, for reasons of both safety and science, carefully controlled clinical trials are necessary.

Clinical trials may put conditions or restrictions on participation that may be perceived as unnecessary but that are critical to obtaining clear, unambiguous results. For example, it is essential that the population participating in the clinical trial be carefully defined and

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relatively homogeneous in certain manifestations and stages of the disease because a given drug may be effective only at a certain stage in the disease process or for a particular subpopulation of patients. Furthermore, there may be circumstances in which the endpoints of drug efficacy are not as dramatic as life and death but may, rather, involve subtle changes in parameters that require careful monitoring. Potentially important results may not be recognized without careful attention to study design and conduct.

Because of the risks inherent in any experiment involving human subjects—and a clinical trial is indeed an experiment—there is a valid and generally agreed-on principle to expose the minimal number of individuals to the risks of the experiment. Nonetheless, many persons with AIDS, desperate for access to any potentially useful drug, argue that they are more than willing to assume such risks.

While greater availability of experimental drugs does offer some initial hope and the immediate gratification of taking some action against this relentless disease, it would be incorrect to equate the showing of compassion with the widespread distribution of untested agents to HIV-infected individuals. Open distribution of unproven therapies is unlikely to help their recipients in the short term and will certainly undermine long-term prospects to conclusively determine effective therapies.

From a purely analytic perspective, there is little disagreement that well-designed clinical trials provide the most efficient mechanism to determine definitively what treatments work. Such clinical trials will ultimately benefit more patients, and sooner, than any other approach. Past experience warns that compromising the precepts of scientific evaluation may lead to deleterious results. Truly effective drugs may be overlooked or discarded, either because of failure to appreciate subtle beneficial effects that might be missed in a poorly designed and implemented trial or because of exaggerated concern about the relative risks of side effects. Conversely, harmful or useless drugs may be accepted for use; such drugs may even be prescribed in lieu of other treatments of more proven benefit. It is only through carefully designed clinical research efforts that definitive answers will be found for this devastating disease—both for those presently suffering from AIDS as well as for the hundreds of thousands of persons who are infected with HIV but not yet sick.

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Without compromising sound scientific principles, there is an ongoing effort to expedite clinical trials. For example, the possibility of shortening the trial process and providing earlier access to experimental drugs that have shown promise of efficacy without serious toxic side effects is under consideration by the FDA. The challenge for policymakers will be to achieve the difficult balance between the rigorous demands of the scientific method necessary to improve therapy and the rights of patients suffering from life-threatening diseases to gain access to new therapies at the earliest possible time.

*Improved Access to Clinical Trials*—In a distinct but related matter, there is a pressing need to provide a broader spectrum of the infected population with greater access to clinical trials of investigational drugs. Clinical research activities are usually conducted at academic medical centers, whereas most patients with HIV infection are cared for in a community setting by nonacademically affiliated providers. Not surprisingly, this situation has been reflected in an underrepresentation of minorities, women, children, hemophiliacs, and those with problems of IV drug use in clinical trials. Future AIDS clinical research efforts must expand the population profile enrolled in clinical trials and foster a greater involvement on the part of community-based primary health-care providers.

Worthwhile opportunities exist to broaden the base of clinical research efforts by increasing the participation of community physicians and patients in both the design and the implementation of AIDS-related research projects. At this time, concerted efforts are being directed toward developing research activities that are innovative and responsive to community needs as well as consistent with sound criteria for scientific research.

Valuable treatment research could be conducted at the community level, including clinical trials of new therapies, but might also involve surveillance of ongoing clinical experience with some of the many therapies being used on an *ad hoc*, "on the streets" basis. In addition, systematic collection of data from actual practice settings—if done prospectively and in a careful, rigorous fashion—could provide very

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useful, albeit exploratory, information about the value of popular but unstudied treatments.

*The Search for a Vaccine*

The development of a vaccine against HIV infection has assumed a prominent position in the strategies for prevention and control of AIDS. However, despite intensive research in this area and considerable scientific advance, there is little hope of having a safe and effective vaccine available in the near future.

Developing a successful vaccine against HIV infection will be difficult for several reasons. The first is due to properties of the virus itself. Many different strains of HIV exist, and even within one person's body the virus can undergo mutations rapidly and easily.[36] In addition, scientists still do not fully understand the nature of an effective immune response that can protect against initial infection or disease progression following infection. The process of vaccine development for other diseases, such as polio and influenza, has been facilitated by the ability to study the nature of the immune response in individuals who have recovered without treatment and then to use their natural immune response as a model for vaccines. AIDS researchers have had no such opportunity, since no one has yet recovered from the disease. The task of researchers in this area is further complicated by the lack of adequate animal models for AIDS.

Despite these handicaps, scientists using knowledge about the structure of the HIV and sound immunologic principles have been attempting to develop a vaccine. The aim is to induce neutralizing antibodies as well as cell-mediated responses against HIV and thereby to protect uninfected individuals against subsequent infection if they are exposed to the virus.

Vaccine development and testing must be carefully designed to ensure that the vaccines will be safe and will elicit an immune response. The approaches to vaccine development that are being explored include the use of whole killed virus, purified natural products of the virus, synthetic preparations of virus components, recombinant DNA products, recombinant vaccinia virus containing parts of the HIV genome, and what is termed anti-idiotype, meaning antibodies generated against antibodies to the virus.[37] To eliminate the possibility that the vaccine itself might be infectious, most AIDS vaccine researchers are using some form of subunit vaccine product

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(consisting of protein components of the virus rather than the whole virus) in their attempts to stimulate immune responses.

The whole killed virus approach raises some concern because of the ability of HIV to integrate into the cell's genetic machinery. Theoretically, a whole killed virus vaccine could introduce viral genetic material into host cells and trigger tumor development or other undesirable side effects. However, given the multiple and variable strains of HIV found, the whole killed virus approach may prove preferable because of its ability to elicit a protective immune response that is effective against many strains of HIV. This hypothesis is based on the observation that the individuals naturally infected with live HIV develop antibodies that are broadly reactive with a range of HIV isolates or strains. In contrast, the immune response to the subunit vaccine appears at this point to be limited to the original strain of virus used to make the vaccine.[38]

To date, some studies using subunit vaccines—in particular those based on segments of the viral envelope—have been shown to stimulate antibody synthesis in rodent and primate models. Certain of the antibodies produced have been shown to be so-called neutralizing antibodies, capable of blocking HIV infection in tissue culture systems. However, the neutralizing antibody responses were unable to protect against subsequent HIV infection in the animals.[39] These findings are in keeping with clinical observations in which no correlation is found between levels of neutralizing antibody and the progression of infection in patients.[40]

In general, candidate vaccines are clinically evaluated in humans only after safety and immunogenicity are demonstrated in laboratory and animal studies. However, given the urgency of the AIDS epidemic, the FDA has approved human trials of a limited number of potential AIDS vaccines, despite the lack of animal data or a clear delineation of the requirements for a protective immune response in humans. Several candidate vaccines are now in the early phases of testing in human volunteers, in both the United States and elsewhere.[41]

A significant dilemma in the evaluation of an AIDS vaccine is how to test candidate vaccines for efficacy. Because AIDS is a fatal disease, it would be ethically unthinkable to deliberately expose a study volunteer to HIV. Therefore, the only available way to show efficacy is to administer the vaccine to a large number of individuals identified

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as being at risk for developing HIV infection and then follow them over a long period of time. If the incidence of new infection in a population at risk is low—as is currently the case for male homosexuals in the United States—literally thousands of people would have to be enrolled in a vaccine trial to achieve meaningful results. Furthermore, ethical considerations would dictate that participants in the vaccine trial receive appropriate instruction about how to avoid HIV infection, making the demonstration of the efficacy of a vaccine still more difficult.

It has been suggested that a candidate vaccine would be most effectively evaluated for efficacy if tested in areas of the world where incidence and prevalence rates for HIV infection are highest. Studies conducted in such locales—including certain developing nations particularly hard hit by the HIV epidemic, such as those of central Africa—would yield more rapid and discernable results, and the potential benefits would be considerable.[42] Nonetheless, vaccine testing in such settings has numerous complications. These include problems of different strains of the virus, difficulties in long-term followup, lack of infrastructure for appropriate clinical evaluation, and multiple social, cultural, and political considerations.

* * *

The magnitude of the AIDS epidemic and the urgency of developing treatments or a cure represent an enormous challenge for biomedical research. Building upon a strong foundation of knowledge accumulated over several decades of research in such fields as immunology, microbiology, infectious diseases, molecular biology, and epidemiology, AIDS research efforts have moved forward swiftly and productively since this new disease was first recognized. Seldom has biomedical science progressed so rapidly, yet real solutions to the control and prevention of HIV infection remain elusive. Perhaps more than any other disease, AIDS has raised a host of complex questions, from the most fundamental nature of biological systems to the role of scientific research in society at large. And beyond the challenge to biomedical research, there are profound and broader implications of the AIDS crisis for many aspects of health care, law, ethics, and society. The needs are tremendous and the answers difficult, but we are moving forward and new solutions are within

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our grasp. The benefits will be far-reaching—not just for AIDS, but for many other areas of health and disease as well.

ENDNOTES

[1]Centers for Disease Control, *Acquired Immunodeficiency Syndrome Weekly Surveillance Report*, (Atlanta, Ga.: Centers for Disease Control, 26 December 1988).

[2]Public Health Service, Department of Health and Human Services, *Quarterly Report to the Domestic Policy Council on the Prevalence and Rate of Spread of HIV in the United States* (Atlanta, Ga.: Centers for Disease Control, July 1988).

[3]P. Piot, F. A. Plummer, F. S. Mhalu, et al., "AIDS: An International Perspective," *Science* 239 (4840) (1988):573–79.

[4]Public Health Service.

[5]M. S. Gottlieb, R. Schroff, H. M. Schanker, et al., "*Pneumocystis Carinii* Pneumonia and Mucosal Candidiasis in Previously Healthy Homosexual Men: Evidence of a New Acquired Cellular Immunodeficiency," *New England Journal of Medicine* 305 (1981):1425–31; and H. Masur, M. A. Michelis, J. B. Greene, et al., "An Outbreak of Community-Acquired *Pneumocystis Carinii* Pneumonia: Initial Manifestation of Cellular Immune Dysfunction," *New England Journal of Medicine* 305 (1981):1431–38.

[6]Masur et al.; and Centers for Disease Control, "Kaposi's Sarcoma and Pneumocystis Pneumonia among Homosexual Men—New York City and California," *Morbidity and Mortality Weekly Report* 30 (3 July 1981):305–8.

[7]Public Health Service; and Centers for Disease Control, "Update on Acquired Immune Deficiency Syndrome (AIDS) United States," *Morbidity and Mortality Weekly Report* 31 (24 September 1982):507–14.

[8]R. C. Gallo, S. Z. Salahuddin, M. Popovic, et al., "Frequent Detection and Isolation of Cytopathic Retroviruses (HTLV-III) from Patients with AIDS and at Risk for AIDS," *Science* 224 (1984):500–502; F. Barre-Sinoussi, J. C. Chermann, F. Rey, et al., "Isolation of a T-Lymphotropic Retrovirus from a Patient at Risk for Acquired Immune Deficiency Syndrome (AIDS)," *Science* 220 (1984):868–71; and J. A. Levy, A. D. Hoffman, S. M. Kramer, et al., "Isolation of Lymphocytopathic Retroviruses from San Francisco Patients with AIDS," *Science* 225 (1984): 840–42.

[9]R. C. Gallo and L. Montagnier, "AIDS in 1988," *Scientific American* 259 (1988): 40–48.

[10]J. W. Curran, H. W. Jaffe, A. M. Hardy, et al., "Epidemiology of HIV Infection and AIDS in the United States," *Science* 239 (4840) (1988):610–16.

[11]Centers for Disease Control, *Acquired Immunodeficiency Syndrome.*

[12]S. Logan, M. Newell, T. Ades, et al., "Breast Feeding and HIV Infection," *Lancet* (11 June 1988):1346.

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ELECTRONIC REPRODUCTION PROHIBITED

[13]M. A. Sande, "Transmission of AIDS: The Case against Casual Contagion," *New England Journal of Medicine* 314 (6) (1986):380–82.

[14]U. S. Congress, Office of Technology Assessment, "Do Insects Transmit AIDS?" a staff paper in OTA's series on AIDS-related issues (Washington, D.C.: Government Printing Office, 1987).

[15]R. R. Redfield and D. S. Burke, "HIV Infection: The Clinical Picture," *Scientific American* 259 (October 1988):90–98.

[16]Curran et al.

[17]Redfield and Burke.

[18]A. B. Rabson and M. A. Martin, "Molecular Organization of the AIDS Retrovirus," *Cell* 40 (1985):477–80.

[19]W. A. Haseltine and F. Wong-Staal, "The Molecular Biology of the AIDS Virus," *Scientific American* 259 (October 1988):52–62.

[20]Ibid.

[21]S. Koenig and A. S. Fauci, "AIDS: Immunopathogenesis and Immune Response to Human Immunodeficiency Virus," in V. T. DeVita, Jr., S. Hellman and S. A. Rosenberg, eds., *AIDS: Etiology, Diagnosis, Treatment, and Prevention*, 2nd ed. (Philadelphia, J. B. Lippincott Company, 1988), 61–77.

[22]S. Broder and A. S. Fauci, "Progress in Drug Therapies for HIV Infection," *Public Health Reports* 103 (May–June 1988):224–28.

[23]Ibid.

[24]Koenig and Fauci.

[25]Ibid.; and T. M. Folks, S. W. Kessler, J. M. Orenstein, et al., "Infection and Replication of Human Immunodeficiency Virus-1 (HIV-1) in Highly Purified Progenitor Cells from Normal Human Bone Marrow," *Science* 242 (1988): 919–22.

[26]R. W. Price, B. Brew, J. Sidtis, et al., "The Brain in AIDS: Central Nervous System HIV-1 Infection and AIDS Dementia Complex," *Science* 239 (4840) (1988):586–92.

[27]S. Kwok, D. H. Mack, K. B. Mullis, et al., "Identification of Human Immunodeficiency Virus Sequences by Using in Vitro Enzymatic Amplification and Oligomer Cleavage Detection," *Journal of Virology* 61 (1987): 1690–94.

[28]A. S. Fauci, "The Human Immunodeficiency Virus: Infectivity and Mechanisms of Pathogenesis," *Science* 239 (4840) (1988):617–22.

[29]Gallo and Montagnier.

[30]Kwok, Mack, Mullis, et al.

[31]Fauci.

[32]Price, Brew, Sidtis, et al.

[33]Folks, Kessler, Orenstein, et al.

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[34]Broder and Fauci.

[35]Ibid.

[36]A. G. Fisher, B. Ensoli, D. Looney, et al., "Biologically Diverse Molecular Variants within a Single HIV-1 Isolate," *Nature* 334 (1988):444–47.

[37]W. C. Koff and D. F. Hoth, "Development and Testing of AIDS Vaccines," *Science* 241 (1988):426–32.

[38]Ibid.

[39]A. M. Prince, B. Horowitz, B. L. Baker, et al., "Failure of an HIV Immune Globulin to Protect Chimpanzees Against Experimental Challenge with HIV," *Proceedings of the National Academy of Sciences* (forthcoming).

[40]Broder and Fauci; and M. Robert-Guroff, M. Brown, and R. C. Gallo, "HTLV-III-neutralizing Antibodies in Patients with AIDS and AIDS-related Complex," *Nature* 316 (1985):72–74.

[41]Koff and Hoth.

[42]Institute of Medicine, *Prospects for Vaccines against HIV Infection*, report of the Conference on Promoting Development of Vaccines Against Human Immunodeficiency Virus Infection and Acquired Immune Deficiency Syndrome (Washington, D.C.: National Academy Press, 14–15 December 1987).

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*Aran Ron, M.D., and David E. Rogers, M.D.*

# AIDS in the United States: Patient Care and Politics

THE APPEARANCE ON THE WORLD SCENE of a new and frightening disease—AIDS, the final, fatal manifestation of infection caused by the human immunodeficiency virus (HIV)—has put a spotlight on how our society responds to a major threat to its health. Diseases like HIV infection, which spread rapidly through communities, particularly those in which person-to-person transmission is evident, evoke fear, sometimes bordering on panic. Public pressure on both scientific and political leaders to "do something quickly" is generally intense.

The response results from the play of many forces—science-based knowledge, social values, religious beliefs, local or regional mores, and the political and economic realities of the times. That this has been true down through the ages is well documented in the article by Charles Rosenberg in this issue detailing responses to epidemics in the past. But in the case of HIV infection and AIDS, perhaps to a greater degree than before, unusual circumstances have led to responses in which social attitudes and values have tended to overwhelm science-based knowledge.

Although most of us would like to believe that we live in a largely rational society, the AIDS epidemic has shown that we do not. This article shows the interplay of social forces, politics, and AIDS as HIV

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infection has evolved in the United States. It traces the parallel emergence of knowledge about the microbe, the disease, its epidemiology, the reaction of various groups to this information, and public reactions to people with AIDS and HIV infection. In the article we examine the influence of these scientific and attitudinal forces on the social and political response to the AIDS epidemic in the United States and use events as they have unfolded in New York City as a case study of how a community severely affected by the AIDS epidemic responds.

## DEVELOPMENT OF SCIENTIFIC KNOWLEDGE ABOUT AIDS

In a significant way, HIV infection has presented a very different situation from that of most epidemics in the past, when neither the etiology was understood nor methods of prevention known. Thanks to remarkable advances in biological research and increasing sophistication of disease surveillance systems, the appearance of this new disease on the U.S. scene was swiftly recognized and knowledge about the clinical characteristics of the illness, the causal agent, its means of transmission, and logical means for its control were developed with impressive speed.

In 1980 the Centers for Disease Control noted an unusual cluster of deaths secondary to pneumocystis pneumonia and Kaposi's sarcoma among homosexual men.[1] The early cases had a characteristic in common—a large number of sexual contacts, many of the cases having traceable contacts to each other. Not long thereafter, intravenous drug users were also found to be coming down with pneumocystis pneumonia. Soon it was evident that the disease was caused by a filterable agent, probably transmitted in a manner similar to hepatitis B—by blood or sexual contact. By 1984, the virus had been identified, the profound immunosuppression of patients with AIDS had been recognized, serologic methods had been developed to detect HIV antibody, the clinical syndromes resulting from HIV infection had become well defined, and the opportunistic infections most commonly seen in conjunction with the infection had been identified. There was hope that drugs to treat it and a vaccine to prevent it would soon follow.

But the human immunodeficiency virus was soon shown to be a formidable foe. A virus of high sophistication had been visited upon

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our high-technology society. It seemed a disease of modern times. Indeed, in the absence of the hollow bore needle, and with the sexual revolution of the 1960s and 1970s and the swiftness and ease of intercontinental air travel, it seems unlikely that HIV infection would have emerged so swiftly or so widely. But even so, it was an unusual virus. The virus could remain silent within the human body for long periods of time, yet the asymptomatic carrier was shown to be capable of transmitting the infection to others. It attacked just the wrong cells. It hid in macrophages and infected the host T cells—cells responsible for an effective and coordinated immunologic response to foreign microbes or cancer, and the virus eluded the body's defenses by locating in these cells. Further, the virus could change its immunologic spots, making it difficult to develop a vaccine to combat it. Unlike most microbes, it was shown to live comfortably with its own neutralizing antibodies. These features made it clear that developing a preventive vaccine or safe and effective therapeutic agents was going to be extraordinarily difficult.

One bright spot, however, was evidence that it was extraordinarily difficult to transmit the agent from person to person. Careful studies of households[2] and health-care workers[3] conclusively demonstrated that the virus was not easily passed from person to person by casual contact. It was shown that the critical factors determining transmission were largely behaviorally controlled—sex and intravenous drug use (the passage of semen or blood from one human to another was required for infection to occur). But here, the parallel and advancing epidemiologic information about the persons who were acquiring HIV infection and developing overt AIDS began to create social, moral, and religious concerns that helped determine the political response to the epidemic.

## SOCIAL AND POLITICAL RESPONSES

Although its epidemiologic characteristics have been quite different in other parts of the world, in the United States AIDS originally emerged in homosexual men, a group commonly evoking strong negative feelings in the larger heterosexual society. To compound public attitudinal problems, the subsequent spread occurred most prominently among IV drug users who were poor, black, or Hispanic. Two groups that society had traditionally stigmatized and shunned, then,

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came to be regarded as the major initial AIDS "risk groups." Swiftly AIDS took on metaphorical characteristics associated with these groups that often evoked hostile reactions. Negative images of these groups caused the expression of thinly disguised feelings as outrageous as "these people are getting what they deserve" and "let AIDS wipe out all of these gays and junkies." Thus powerful negative social and moral attitudes legitimatized a slow and sometimes reluctant public response.

Further, to our society, which had come to expect science to apply quick technical solutions to problems of illness, the clear evidence that there was to be no quick and easy biomedical technical fix was a disappointment. Other evidence that education, behavioral change, and response at a social and political level could control the disease was also available, but for reasons already outlined, making use of this evidence was a response much more difficult to set in motion. While the public has usually accepted new technological science-based solutions to problems promptly, our social and behavioral reflexes change much more slowly. Social, moral, religious, and political groups were reluctant to set in motion the explicit kinds of intense educational programs that would initiate the necessary behavioral changes.

Contributing further to this stalemate were at least four other forces. First, the way the disease was portrayed in the media; second, the initial response in persons in the homosexual community to evidence about the means of the disease's spread and their role in it; third, the behavior of certain opinion makers; and fourth, the focal and circumscribed geographic nature of the epidemic.

The media frame issues for the public and often help determine the political agenda for our nation. Government responses frequently depend on attitudes generated by media attention, and studies show that people get many of their facts, ideas, and attitudes about social issues from television, newspapers, and magazines.[4] In this instance, the press and the media did little to encourage a swift public response. After initially reporting the discovery of this new and fatal disease in 1981, and characterizing it as a disease of gay men and not a threat to the general public, the press essentially ignored the topic for almost two years. AIDS was viewed as a gay story that did not deserve general attention. At a forum organized by the Scientists' Institute for Public Information it was stated that "it would be dishonest not to

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say that we couldn't sell the AIDS story early on because it was about gays."[5] As it became apparent that the disease also involved IV drug users, both homosexuals and IV drug users with AIDS were portrayed in the media as individuals responsible for their own illnesses. Frequently they were perceived as guilty and therefore less deserving of resources and care for their illness. Only those who were viewed as innocent bystanders—children born of HIV-positive mothers, hemophiliacs, and others acquiring AIDS through transfusion were portrayed as deserving of the benefits that other sick persons receive. It took a rather regrettable choice of words by a respected public official, Dr. Anthony Fauci of the National Institute of Allergy and Infectious Disease, in a 1983 issue of the *Journal of the American Medical Association* to stir up media coverage.[6] He stated that AIDS might be transmissible to the heterosexual population by "routine close contact." This suggestion that the disease might spread to the general population led to a quadrupling of articles about AIDS and finally, in 1983, it came to be regarded as relevant to the welfare of the general population.

A second cause of the unwillingness of the heterosexual community to respond promptly was the lack of clear and unified response by the homosexual community early in the AIDS epidemic. In the gay liberation movement of the 1970s, sex became a political statement, and sexual freedom a central part of political liberation for the gay community. For years the homosexual community had fought to limit government intervention in its affairs. Despite mounting evidence that having many casual sexual partners led to rapid spread of the infection, early on a number of homosexual organizations resisted the closure of bath houses and sex clubs, where high-risk sexual encounters took place, and some gays denied that their own behavior contributed to the spread of HIV infection. Their resistance angered the broader community and again, retarded action.

Third, the behavior and public statements of certain powerful opinion leaders did little to encourage swift public action to control the disease. Statements such as "AIDS is the wrath of God visited upon the homosexuals"[7] and the suggestion that all HIV-positive individuals be forcibly tattooed and separated from the rest of society in isolated communities not unlike leper colonies of the past[8] encouraged and legitimized hostility directed at the groups most heavily hit by AIDS. In Florida, the burning of the home of three

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hemophiliac children with AIDS was eerily reminiscent of the burning of Jews blamed for bubonic plague in Europe 600 years earlier and an example of how deep the fear and anger in some quarters were.

Fourth, the geographically focal and selective nature of the epidemic tended to encourage national inaction. Clearly, the massive spread of the virus, with an estimated 1 million to 1.5 million Americans infected and 70,000 cases of overt AIDS reported by mid-1988, merited an aggressive federal response. But the fact that only five states (New York, New Jersey, California, Florida, and Texas) had more than two-thirds of all the cases tended to blunt the political interest from many states. Indeed, five states—Vermont, Idaho, Montana, and the Dakotas—had each had fewer than 10 cases in eight years.[9] Their legislators were understandably averse to giving up funds necessary for education, transportation, or other crying needs of their constituents to serve those who had questionable life-styles and HIV infections and who lived in large urban centers.

The chasm between those affected by AIDS and political leaders widened as the disease spread rapidly among IV drug users, a group with no political constituency in any quarter. In San Francisco, where gay political power was important and respected, monies and services were put in place to care for AIDS patients. Most cities, however, provided few funds for such services.

As might be anticipated, this kind of climate translated into slow and penurious federal funding. During the first eighteen months of the AIDS epidemic, by which time several hundred cases of AIDS had been identified, only $2 million had been given to the Centers for Disease Control in Atlanta to study AIDS. Such inadequate appropriations severely hampered early efforts to study and track the disease and the response to the growing epidemic. That the epidemic came when the nation was committing itself to limited government and nonmilitary budget retrenchment added to the problem. Thus during the first four or five years of the AIDS epidemic, Congress and the administration played a ritualistic fiscal game. The administration would oppose any extra money for AIDS and instruct its agency chiefs to argue that the money was not needed. Timothy Westmoreland, a staff member of the Health Subcommittee of the U.S. House of Representatives has observed that:

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> the administration sends United States Public Health Service scientists, otherwise very credible people, day after day to commit virtual perjury before Congress on issues [of] . . . AIDS funding. . . . These scientists testify that administration budgets are adequate, and that all is being done that can be done. Then, these same officials go back and write desperate memoranda to the OMB [Office of Management and Budget] about what will happen if they don't have more personnel or greater access to funds.[10]

Despite this climate, there was progress. Because of advancing evidence that the disease was serious, Congress would often pass on additional funds for AIDS anyway, and for political reasons the administration did not veto them. Eventually Congress made monies available but often much later than appropriate. In a 1985 report the Office of Technology Assessment declared that "while the Federal Government has designated AIDS our number one health priority, increases in fundings specifically for AIDS activities have come at the initiative of Congress, and Public Health Service agencies have had difficulties in planning their AIDS related activities."[11]

In the early 1980s, the funds for AIDS were minimal compared with those for other diseases emerging as public concerns. For example, in 1981 and 1982, the National Institutes of Health spent funds amounting to $36,100 for each death due to toxic shock syndrome and $34,841 for each death resulting from legionnaires' disease. Compare this level of spending with the $3,225 spent in 1981 and the $8,991 spent in 1982 for each AIDS death.[12] It was clear that an administration facing major increases in military outlays and an expanding budgetary deficit would not push for a large expansion of funds to fight an epidemic viewed as primarily confined to such politically unpopular groups as homosexuals and IV drug users.

Today, despite increasing public media attention to AIDS, widespread public fear and hostility remain. Public opinion polls indicate that a large number of Americans, even when at low risk themselves, continue to express fear and intolerance toward people with AIDS.[13]

Recent efforts to develop well-targeted, unequivocal, and explicit educational messages designed to promote behavioral change remain entangled in a morass of moral arguments. Those arguments center on the appropriateness of information campaigns that allow individuals to continue behavior many consider morally wrong. The hand-

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book *AIDS and Our Children*, released by the Department of Education, focuses on sexual abstinence and monogamy as cornerstones of AIDS education while it plays down the value of condoms and the importance of clean needles to those continuing IV drug use. The use of federal funds for education material that is directed to homosexuals or that does not emphasize monogamous heterosexual marriage and abstinence from IV drug abuse is legislatively prohibited. Although we have considerable detailed knowledge about the ways in which the AIDS virus is transmitted, we are failing to give life-saving education to those at highest risk.

## NEW YORK CITY: A CASE STUDY

New York City has been the epicenter of the epidemic. At one point, close to half the nation's cases were in the five boroughs. The magnitude of the problem and such a concentration of cases could have galvanized the most aggressive and forceful local response in the nation. But as already outlined, the divisive nature of attitudes about the disease, the inability of advocacy groups to effectively pressure a city government already trying to deal with a multitude of problems, minimal federal support, lack of cooperation between city and state agencies, and the resilience of a complex web of bureaucratic obstacles at all levels has left the city in the ninth year of the epidemic still marginally able to cope with AIDS and without any well-coordinated disciplined approach to the HIV epidemic.

The statistics for AIDS in New York City are sobering. At this writing, New York City's over 20,000 cases account for almost 25 percent of the cases in the United States. There has been a total of almost 10,000 AIDS deaths in the city. AIDS is now the leading cause of death among men of twenty-five to forty-four and women of twenty-five to thirty-four in New York City.[14] Somewhere between 160,000 and 360,000 New Yorkers are estimated to be HIV infected and infectious to others. The number of new cases of AIDS diagnosed in the city each month now approaches 500, and the demography of those afflicted is changing.[15] Today intravenous drug use is the primary risk factor in most of these new cases, and more than 50 percent of the city's 200,000 IV drug users are believed to be infected with the human immunodeficiency virus.[16] It is estimated that 10 percent to 30 percent of the 30,000 to 90,000 homeless people in

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New York City carry the virus. The children diagnosed with AIDS in New York City now number about 400. The acute-care hospitals of the city, many with occupancies of greater than 95 percent, are straining to deal with AIDS patients, who now occupy 1,400 hospital beds daily, and this number is rising. Health-care crisis is much in the newspapers and much on the minds of New Yorkers.

*History of AIDS in New York City*

AIDS was first recognized among homosexuals in Los Angeles and New York City in 1981, and by mid-1982 the epidemic was well under way in these cities as well as in San Francisco. During the first three years of the epidemic, the number of diagnosed cases of AIDS in New York City more than tripled each year, with 30 cases in 1980, 142 in 1981, and 499 in 1982. Initially, almost all cases identified occurred in male homosexuals, and the association was such that at one point AIDS was known by the acronym GRID, for gay-related immunodeficiency syndrome. But starting in 1983 and 1984, intravenous drug users began forming an increasing number of the AIDS cases. IV drug users also began dying at much faster rates from bacterial pneumonia and endocarditis, now recognized to be accompaniments of HIV infection and its immunosuppression.

The rising number of intravenous drug users with HIV-related diseases changed the nature of the epidemic in New York City. The infection began to spread among nonhomosexual groups. Intravenous drug users transmitted the human immunodeficiency virus to their sexual partners, usually male to female, and infected women in turn infected their offspring. A recent study shows that in some areas of New York City more than 2 percent of newborn babies have HIV antibody.[17] It is now clear that 30 percent to 50 percent of such children are actively infected and will develop the fatal disease. Through intravenous drug use, AIDS has also found its way into the city's prison system. Of the 718 prison inmates diagnosed with AIDS (probably a gross undercount), 86 percent have identified IV drug use as their primary risk factor.[18] IV drug use seems the route whereby many of the homeless have developed AIDS, although here the sequence has gone both ways. Some who develop AIDS lose their homes because of eviction or inability to pay rent; some who are homeless acquire HIV infection through IV drug use. Through it all,

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AIDS has increasingly become the scourge of poor black and poor Hispanic IV drug users who live in New York City.

*Factors Affecting New York City's Response to the Epidemic*

The forces influencing the national response to the epidemic already outlined have of course had an impact on local communities. In New York City, the major forces affecting the response are the ones we have already outlined, but the financial and political isolation of the city by the federal and state governments, the reluctance to adopt genuine crisis measures to circumvent city and state bureaucratic obstacles, and the reluctance to place real authority for AIDS decisions in one central figure or body have added to the problem.

In New York City the political influence of homosexuals has not been impressive. As IV drug users became HIV-infected, the use of crack went up, and violence erupted, AIDS was viewed with increasing negativity. Homosexuals and IV drug users found little sympathy in the competitive and bottom-line-oriented environment of New York City. Many New Yorkers believed that these groups had brought this plight upon themselves. In San Francisco the homosexual community, local government, and voluntary organizations were able to cooperate in the development of programs devoted to caring for the needs of those affected by the epidemic. But this was not the case early in the epidemic in New York City. The New York homosexual community, less well organized than its San Francisco counterpart, was unable to pressure the city government for a significant commitment of resources and personnel to deal with AIDS and found itself lost among the many diverse groups crying out for help. The New York homosexual community was left by itself to provide many of the support programs normally expected of city social services. The Gay Men's Health Crisis was a purely voluntary effort, and through it, many of the programs critical to the care of people with AIDS were developed. This organization also helped develop the AIDS Institute, a creation of the New York State Health Department to funnel funds for HIV testing, counseling, research, and treatment to appropriate organizations, including GMHC.

Other groups with high rates of HIV infection, such as IV drug users, prison inmates, and the homeless, fared even more poorly. And as the poor, black, and Hispanic communities, already suffering from agonizing problems of poverty and crime, were further overwhelmed

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by the deadly combination of AIDS and substance abuse, AIDS came to be viewed simply as another burden on these communities rather than a crisis situation that required drastic action.

We have stated that the public's attitude and perception of the epidemic was, and continues to be, largely shaped by the media. Again, New York City illustrates the point. During the first few years, coverage of the epidemic in the city received scant attention through the major papers. The *New York Times* wrote only three stories on the epidemic in 1981 and 1982, and none of those articles made it to the front page. And in the absence of any public pressure, despite vigorous efforts by the city commissioner of health, no influential city official was interested in leading a campaign against AIDS. As the epidemic progressed and heterosexual spread became evident, however, the media suddenly discovered AIDS. Public awareness rose. The passion of certain groups of New Yorkers became so inflamed at times that rational responses were difficult to implement. One example of this problem is the "NIMBY," the "not in my backyard" syndrome. Neighborhoods have reacted violently to attempts to develop nursing-home and residential units, housing and ambulatory-care programs, and new drug-treatment centers for AIDS patients. The list of new programs blocked by such reactions is long. Another example of the emotional responses surrounding AIDS issues is the accusation of some groups that New York City's health department has dropped its estimated number of HIV-infected New Yorkers from 400,000 to 200,000 just to decrease the allocation of resources for combating AIDS. Although such a drop would usually be regarded as good news, the revised estimate provoked rapid and extremely harsh criticism from gay organizations.

As the costs involved in treating the large number of AIDS patients steadily grew, New York City found itself increasingly isolated not only from the federal government but frequently from the state as well. The overwhelming majority of AIDS cases in New York are within the city (more than 95 percent). Based in Albany, and with a preponderance of legislators from non-AIDS-affected regions, many in New York State government felt far removed from the epicenter of the epidemic and were hard to convince that indeed "crisis" was upon them. Further, in a period of budget crunch many legislators were reluctant to appropriate funds for programs that had little relevance to their local constituencies and did nothing to serve their

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local needs. Thanks to the efforts of a determined state commissioner of health, significant amounts of state funds have been allocated to dealing with AIDS and in rapidly increasing amounts each year. But it is clear that the needs far surpass one state's capacity to fund them. As an example, the AIDS Institute had 1988 funding in excess of $200 million but presented a list of unfunded vital new programs costing in excess of $1.6 billion.

Only federal resources can fill such gaps, and such help has not been forthcoming. To further compound the problem, even within New York City, resources are inequitably distributed. Frequently, because of IV drug use, the poorer and less influential areas of the city have far higher levels of HIV-related disease but fewer resources to deal with them. In a situation of resources far short of need, each level of government looks to another to take on an additional share, and each serves as a convenient scapegoat for others on which to blame the failure for the inadequate level of services.

Lastly, the failure to vest both the responsibilities and the authority for direction of all AIDS plans and programs in one well-identified office or person has permitted bureaucratic obstacles to impede many of the efforts of New York City's dedicated social-service and health agencies to get their jobs done swiftly. Thus, education and preventive programs have been delayed for years as issues of content and appropriateness have been debated. Drug-treatment programs meeting stiff neighborhood opposition as well as financial and personnel shortages have been unable to expand. In the prisons, authorities have had difficulty admitting that sexual relations and drug use occur, impeding any useful response to the spread of AIDS in this setting. The city, struggling to deal with an overwhelming homeless problem, has been unable to meet the special needs of those with AIDS who are without shelter. Community groups willing to buy, renovate, and run nursing homes, residential units, and the like have been unable to open such units because of requirements and delays caused by multiple city agencies having to approve and sign off on such projects. And such delays can stretch from months to years despite the mounting numbers of AIDS cases. That many of these agencies were established to foster the very kinds of program they

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have been delaying attests to the lack of a tough crisis-oriented approach to the HIV epidemic.

*The Current Situation*

This combination of factors has left New York City with a health system that is overstressed, understaffed, and underfunded. The New York City AIDS Task Force as well as most of the city's newspapers say that the system is in a state of crisis. By default, much of the burden of caring for persons with AIDS has fallen to the acute-care hospitals. These hospitals, which must also deal with the medical, psychological, and social complications of the drug-use, alcoholism, homeless, and poverty cases that have found their way into the hospital system, are in serious trouble. Not accustomed or well prepared to deal with these social issues, the hospital system is in a medical gridlock. Many hospitals are frequently so overloaded that they are having extreme difficulty caring not only for those with AIDS but also those with other sicknesses. Inequity in sharing the care of AIDS patients has led to hostility between the municipal and the voluntary sectors of the health system. The reluctance of some of the voluntary hospitals to care for AIDS patients out of fear of being branded AIDS hospitals has resulted in the city's Health and Hospitals Corporation hospitals, with 15 percent of the city's hospital capacity, taking care of 35 percent of the city's AIDS patients.

Long-term-care beds and nursing-home facilities are seriously lacking. While more than 1,000 nursing-home beds are already needed for AIDS patients, only 44 such beds exist in the entire city. No voluntary nursing homes accept AIDS patients. Thus, AIDS patients frequently remain in acute-care hospitals for days and weeks beyond medical need because of the lack of other sites for care. Lengths of stay for AIDS patients in New York City hospitals, already the longest and most expensive of any major city in the United States, are actually continuing to increase because of the lack of alternate care facilities. Babies abandoned or orphaned by parents with AIDS have until recently spent months or years living in hospitals because of the lack of foster or residential care facilities. Residential units and ambulatory-care programs are in short supply.

Further compounding the problem, many hospitals and other facilities are unable to meet the health-care needs of persons with AIDS and HIV-related diseases because of the shortage of trained

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personnel. Despite a desperate need for additional hospital beds, many units are closed because of a shortage of nurses. In addition, there is a serious shortage of social workers, counselors, home health workers, and others who can work or support people with HIV-related illness. Few private physicians are sufficiently trained or experienced to properly care for persons with AIDS.

Although New York City's health commissioner has repeatedly stated that the future of the AIDS epidemic lies in combating intravenous drug use, no new drug-treatment programs have opened in the past decade and there are only about 35,000 treatment slots to accommodate an estimated 200,000 IV drug users. A needle-exchange program proposed several years ago has finally been initiated, but in the face of intense opposition from the black community. Consequently, thousands of addicts, unable to obtain treatment or clean needles, continue to become HIV infected and infectious to others.

New York will face two grim scenarios in the future: a rise in racial and social conflicts as acute-care resources grow scarce and the inability to accommodate all the additional patients who will appear in response to any advances in the treatment of HIV infection.

Arranging admission to New York City hospitals for patients with acute illnesses is already very difficult. There are increasing numbers of reports of patients who wait for days in emergency departments before hospital beds become available. Elective admissions are also becoming difficult to arrange. If care for persons with AIDS is perceived as interfering with the health care of others, or if hospitals are unable to admit patients with other life-threatening problems because of their AIDS patient census, bitter social conflicts with racial overtones may erupt.

Very likely, the next breakthrough in the treatment of HIV infection will be a pharmaceutical agent that can delay the onset of symptomatic disease in healthy persons infected with the HIV virus. Consider what this will mean for the New York City health-care system. Because it will be to each person's advantage to know his or her HIV status, the 160,000 to 360,000 New Yorkers who are HIV positive must be found among the population of 8 million. The logistics and cost of such a case finding will be monumental. Because treatment of this group will require medical supervision (the drug will probably be toxic), the capacity of New York City's medical system

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to manage these thousands of additional patients will be stretched beyond its limit, even if the problems of confidentiality, discrimination, and payment for medical services are overcome.

While there have been many heroes and heroines—doctors, nurses, public-health officials, voluntary organizations, and institutions—that have given selfless, unstinting care and service, New York City's health-care system, at the center of the epidemic, has moved to a state of crisis.

## EPILOGUE

What have we learned from our experience with the epidemic of our times? A great deal. We have developed much new science-based information about the agent and the disease it causes, and we know more about how our society reacts to a problem that initially strikes those with whom the majority of the public feels uncomfortable. That there has been a certain disconnectedness in our responses to the epidemic is undeniable. But it is also clear that while science cannot make policy, it can be an important shaping force. While some of the loud voices called for repressive measures like tattoos, quarantines, mandatory tests, and denial of information about transmission of HIV infection to certain groups, Congress has continued to allocate increasing funds for AIDS each year. The public in California has rejected Proposition 102 (to legislate mandatory testing and reporting of HIV status), the courts have consistently refused to support mandatory HIV testing, and educational materials have grown increasingly explicit. Clearly, "medicalizing" AIDS has had certain advantages. It has permitted many to view AIDS less judgmentally. We hope our public and political responses will grow yet more forceful and effective in the years to come.

Throughout the nine-year history of the AIDS epidemic, heroic leaders have sought to keep the disease on the public agenda, fought for funds to treat and care for AIDS patients, and struggled for research resources necessary to understand and cope with the infection.

The increasing horror of a disease that has inexorably claimed thousands of lives has demanded and is now resulting in an increasingly aggressive social and political response. The first sign of a remarkable change in public posture was the publication of the *Report of the President's Commission on the Human Immunodefi-*

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*ciency Virus Epidemic.*[19] This courageous document presents the most current scientific data and a series of recommendations that, if appropriately implemented, would markedly improve our approach to HIV infection and AIDS.

A second sign of change in the public's response to AIDS was the steady increase in funding for AIDS. Thanks to the dedicated efforts of individuals like Congressman Henry Waxman, the Department of Health and Human Services spent over $1 billion in 1987 for biomedical research, public-health measures, and medical services, mostly through Medicaid.[20] Congressman Waxman's consistent reelection to his post despite his early and outspoken advocacy for the AIDS crisis shows the interesting national schizophrenia with which we approach such problems.

A third sign was the passage in New York State of a model confidentiality bill, soon to be followed, we hope, by similar legislation at the federal level. This bill may encourage people to determine their HIV status. Obviously, much more knowledge about the incidence of HIV infection is needed for planning, tracking the course of the epidemic, and managing those with both symptomatic and asymptomatic infection. People are not likely to freely submit to testing unless tough confidentiality and antidiscrimination laws are passed and strictly enforced. These laws are only now beginning to appear on the scene and still face considerable resistance from some groups, but they are appearing.

A fourth sign of change has been the increasing attention paid to drug abuse and the mounting pressure to make treatment available on demand to IV drug users. Prevention of the start of drug use and the interdiction of drugs have now become federal priorities. Many localities have intensified efforts to open new treatment programs despite neighborhood resistance.

A fifth sign of change is the evidence that targeted and explicit education can alter behavior and reduce the transmission of HIV infection. Profound behavioral change has occurred in the gay community, and the resultant plateauing of HIV seroprevalence in this group is encouraging. There is hope that this change will lead to a great augmentation of educational efforts, presently our only way to prevent the spread of the disease.

AIDS has caused us to scrutinize many of the social and political issues that divide American society and has highlighted many of the

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weaknesses and faults in our medical and social-support systems. We may learn to do better from this experience. By designing appropriate economic, political, and medical responses to AIDS, we will at the same time be addressing other pressing public-health and social problems. For example, the financial response to the AIDS epidemic may have enormous significance to the over 37 million people without adequate health insurance. Further, by learning how to treat AIDS patients more effectively, we may be better able to deal with those with other chronic illnesses, such as Alzheimer's disease, crippling arthritis, and congestive heart failure.

AIDS is challenging us to rise above our differences and to take decisive and constructive action to deal with a common threat. Our society must decide how it is to care for a disease that has disproportionately affected those not well regarded by the larger public. That this is a difficult, sensitive, and demanding task is evident from what has been done and not done. The story of HIV infection in New York City, its many tragedies and its fewer triumphs, vividly illustrates the nature of the problem. It would be naive and probably wrong to suggest that informed public policy can or should flow, value free, from science-based knowledge. A dictatorship of science, no matter how benevolent, would be as hazardous as any other single-minded autocracy. As AIDS has made apparent, a response with the proper blend of science, compassion, and social values is hard to orchestrate. But in struggling to cope with AIDS, we can hope to become a more tolerant, flexible society aspiring to certain timeless values and standards in dealing with everyone who needs our care and support.

ENDNOTES

[1]Kaposi's sarcoma and pneumocystis pneumonia among homosexual men in New York City and California. See *Morbidity and Mortality Weekly Report* 30 (3 July 1981):305–8.

[2]G. H. Friedland, B. R. Saltzman, F. Rogers, P. A. Kuhl, M. L. Lesser, M. M. Mayors, and R. S. Klein, "Lack of Transmission of HTLV-III/LAV Infection to Household Contacts of Patients with AIDS Related Complex with Oral Candidiasis," *New England Journal of Medicine* 314 (6 February 1986):344–49.

[3]E. McCray, "The Cooperative Needlestick Surveillance Group; Occupational Risk of the Acquired Immunodeficiency Virus among Health Care Workers," *New England Journal of Medicine* 314 (24 April 1986):1127–32.

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[4]G. Tuchman, A. K. Daniels, and J. Benet, *Hearth and Home: Images of Women in the Mass Media* (New York: Oxford University Press, 1978).

[5]C. Guilfoy, "AIDS Forum: Politics and Science Collide," *Gay Community News*, 23 February 1983.

[6]Anthony Fauci, "The Acquired Immune Deficiency Syndrome: The Ever Broadening Clinical Syndrome," *Journal of the American Medical Association* 249 (6 May 1980):2375–76.

[7]D. Altman, *AIDS in the Mind of America* (Garden City, N.Y.: Anchor Press, Doubleday, 1987).

[8]William F. Buckley, "Identify All Carriers," *New York Times*, 18 March 1986.

[9]United States AIDS Program, *AIDS Weekly Surveillance Report* (Atlanta, Ga.: Center for Infectious Diseases, Centers for Disease Control, 6 June 1988).

[10]Timothy Westmoreland, "AIDS and the Political Process: A Federal Perspective," in *AIDS, Public Policy Dimensions* (New York: United Hospital Fund and the Institute for Health Policy Studies, 1987).

[11]Office of Technology Assessment, *Review of The Public Health Services Response to AIDS, A Technical Memorandum* (Washington, D.C.: United States Printing Office, February 1985).

[12]Randy Shilts, *And the Band Played On* (New York: St. Martins Press, 1987), 186.

[13]Robert J. and K. Donelan, "Discrimination Against People with AIDS: The Public's Perspective," *New England Journal of Medicine* 319 (13 October 1988): 1022–26.

[14]Address by Dr. Stephen Joseph, commissioner of health, New York City, presented at the American Public Health Association Physicians' Forum dinner, 18 October 1987.

[15]AIDS Surveillance Unit, *AIDS Surveillance Update* (New York: New York City Department of Health, 30 November 1988).

[16]Address by Dr. Joseph.

[17]Bruce Lambert, "Study Finds Antibodies for AIDS in 1 in 61 Babies in New York City," *New York Times*, 13 January 1988.

[18]Bureau of Communicable Disease Control, *AIDS Surveillance Monthly Update* (Albany, N.Y.: New York State Department of Health, June-July 1988).

[19]*Report of the Presidential Commission on the Human Immunodeficiency Virus Epidemic*, 0–214–701: Q3 (Washington, D.C.: United States Printing Office, 1988).

[20]J. K. Inglehart, "Financing the Struggle against AIDS," *New England Journal of Medicine* 317 (16 July 1987):180–84.

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*Gerald H. Friedland, M.D.*

# Clinical Care in the AIDS Epidemic

*The word plague had just been uttered for the first time. Everybody knows that pestilences have a way of recurring in the world; yet somehow we find it hard to believe in ones that crash down on our heads from a blue sky. There have been as many plagues as wars in history; yet always plagues and wars take people equally by surprise. . . . Our townsfolk were not more to blame than others; they forgot to be modest, that was all, and thought that everything was still possible for them; which presumed that pestilences were impossible. . . . They fancied themselves free, and no one will ever be free so long as there are pestilences.*

—Albert Camus[1]

THE LAST THING I HAD TIME FOR on that busy autumn morning in 1983 was a telephone call about an AIDS patient in distress. Clinical teaching rounds with interns and residents were about to begin, and I was scheduled to lecture later that morning.

"The parents of your patient Jose Quintero told me to call you," a nurse exclaimed anxiously.

I had seen Jose the evening before and knew he was soon to die. Years of cocaine abuse and careless sex had brought him to the edge.

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AIDS had been particularly cruel to him—multiple hospitalizations for pneumocystis pneumonia, fevers, pain, emaciation, and now swelling of his small body and another episode of pneumonia. He was an impossibly angry man, demanding of everyone with such urgency and insistence that both his family and the doctors and nurses caring for him often found it hard to be compassionate. But he elicited a grudging respect as well. Although his anger was diffuse and unfocused, nothing made him more angry than this illness. He accepted neither his disease nor its resultant disabilities. When he was no longer able to drive his taxi, he had his father drive it for him while he sat in the front seat going through the motions of his business. Rarely keeping routine clinic appointments, instead he usually showed up only when he was sick and always expected immediate care. Each diagnostic test and therapeutic maneuver offered to him he met first with sneering refusal, yet eventually he would reluctantly agree to it. I knew he was grateful for our efforts, but he hated his dependency and loss of control. Never ceasing to fight with us and his disease, Jose lived longer than we had expected. I used to quip that he was so angry he scared his dwindling immune system into working overtime to keep him alive. Earlier in the week, after we discussed his illness and prognosis, he and his family decided that if he required intubation—being placed on a respirator—he would refuse and take his chances. He knew his death was imminent, and he was not going to be dependent on a machine to keep him alive.

"He's asking for you, and I think you should come as quickly as you can," the nurse on the phone insisted.

I momentarily worried about not meeting my organized schedule for the day but went off to Jose's room. There he sat, still alive, upright in a chair beside his bed, bloated and breathing fitfully, an oxygen mask over his mouth and an intravenous line in one arm. His parents were hovering nearby, and the young nurse who had called me was sitting at his side. He grasped her hand tightly, holding onto her as his life ebbed. She had cared for him the previous day, and moved by his courage and recognizing his final stage of illness, had chosen to stay through the night with him. As I stepped into the room, he lifted his swollen eyelids, stared directly into my eyes, and slowly nodded.

In the spring of 1981, I returned to live and work as a physician in New York City after a thirteen-year absence. I came to Montefiore

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Medical Center/North Central Bronx Hospital and Albert Einstein College of Medicine in the Bronx, a borough of New York City, to help supervise the training of medical students and young physicians in internal medicine and to teach infectious diseases. This was the specialty in which I had been trained and which I had practiced for over a decade in the United States, Africa, and the Middle East.

In August of 1981, I saw the first three patients with *Pneumocystis carinii* pneumonia. They were desperately ill young men, and two of them were on respirators. A similar bizarre illness had been reported among gay men in California and New York City earlier in the summer, but these three men were not gay. Instead, all had histories of intravenous drug use. I recalled that a young woman with the same mysterious illness had been cared for during the previous spring at Montefiore, and we later learned that her infant had also been hospitalized with an unusual and unknown immunodeficiency. I can remember a mixture of feelings at the time—dispassionate clinical interest in what appeared to be a most unusual and challenging cluster of cases, personal distress at the terror and pain of those young men whose lungs could no longer bear the assault of infection and whose lives were hanging in the balance on those mechanical respirators, a clear and deep sense of disbelief, foreboding, and dread—that something not only different and unusual but also cruel and malevolent was occurring, and that this was just the beginning.

During the first year of what we now know to be the AIDS epidemic, an additional fourteen patients were diagnosed with the still unnamed syndrome at my institution. During the second year, the number doubled.

I remember a disturbing recurring dream in those early years. I was walking along Jerome Avenue in the Bronx at midday. I felt the vibration of the overhead subway trains, but there was no sound. Buses maneuvered through the lines of double-parked cars and greengrocer stands pushed onto the sidewalk with bins of tropical fruit, but there was no color. Everything looked right and as it should have been, but there were no people; the silent, secret epidemic had carried them away. I've long since stopped having this dream, but flashes of its images sometimes break into my consciousness.

Since the early 1980s remarkable biologic, epidemiologic, and clinical progress has been made in the AIDS epidemic. The human immunodeficiency virus (HIV) causing AIDS and other related illness

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has been discovered, characterized, and examined.[2] Its routes of transmission have been carefully documented, and the ways in which it is not transmitted have been established as well.[3] Surveillance methodologies have been elaborated so that the numerical and geographic extent of infection and disease have been tracked,[4] and a fuller appreciation of the spectrum of illness induced by HIV has evolved.[5] Clinical diagnosis and treatment of both HIV infection and the myriad of complicating secondary infections and malignancies have progressed both in specific instances and on a broad and advancing front.[6] Some relevant and innovative systems of care for HIV-infected persons and those with AIDS have been developed,[7] and finally, local as well as larger national and international societies in which HIV infection occurs have slowly responded in policy and allocation of resources.[8]

As this exceptional progress has taken place and even accelerated, the number of new cases of AIDS has multiplied. By September 1988, seven years after those initial three cases were diagnosed, over 800 men, women, and children have been diagnosed with AIDS at the hospitals in which I work. During this time 16,663 cases have been diagnosed in New York City,[9] 72,645 in the United States,[10] and more than 250,000 cases in the entire world.[11] These, of course, represent the tip of the iceberg of HIV infection, now estimated to be between 5 million and 10 million worldwide.[12] At my institution and elsewhere, most patients diagnosed with AIDS during the past seven years have now died or are in the terminal stages of their illness. Their median life expectancy from time of diagnosis of AIDS to death has been less than a year.[13] Some have survived substantially longer, and others have succumbed quickly. I've learned to believe that the angry patients are likely to live longer—that fighting with their disease and care providers, as Jose did, is better than passivity and acceptance. But ultimately for all, the outcome is the same—a cruel, progressive, lingering demise. Epidemiologic studies have demonstrated that almost half those infected with HIV will develop AIDS within ten years,[14] and the proportion rises with each year, so that at the very least the majority, if not all, will develop AIDS. Thus, the full force of the HIV epidemic has not yet been experienced; the worst is yet to come. Indeed, the simple, irrefutable fact is that we are at the beginning of the epidemic. Although of great consequence worldwide, this fact is of special significance in areas of high prevalence like

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central Africa and New York City. Only a few years ago, new cases appeared at my institution in the Bronx at the rate of 1 or 2 per month. Now approximately 5 new cases are seen each week and added to our patient roster. On any day of the week, 50 to 60 patients with AIDS are hospitalized in our wards. In New York City in June 1988, 1,498 acute-care beds were in use citywide for AIDS patients, representing 6 percent of all medical-surgical beds in the city.[15] The need for acute-care beds for AIDS patients will increase to 2,700 by 1991, or 11 percent of the total hospital beds in New York City.[16] Some projections forecast that up to one-third of all beds in New York City will be occupied by AIDS cases by 1991.[17] Projections based on New York City AIDS cases already reported indicate that in 1991 between 7,876 and 11,232 new cases will be diagnosed—possibly more cases in one year than in the first seven years of the epidemic.[18] During this year, there may be 10,000 persons alive with AIDS, and perhaps 100,000 living persons will have AIDS-related illness.

The statistics of epidemiology are human beings with the tears removed. They capture the number of sufferers but not the quality or the weight of the suffering that is being endured, for the fundamental reality of AIDS is that it slowly, prematurely, and with great cruelty robs young men and women of their function, their plans and dreams, and ultimately, their lives. Further, the numbers do not capture the profound effect of the epidemic on health-care workers, who by the nature of their work have been placed in the path of the epidemic.

In my professional routine and that of my colleagues, what was initially an exotic curiosity has now become our daily fare. Among health-care workers, including myself, the initial interest and even clinical excitement about a new disease has long since given way under the weight of the steady, unrelenting procession of new patients. Challenging but disturbing personal and professional ethical issues have surfaced, including the appropriateness of treatment in the terminal stages of illness, the limits of confidentiality of medical information, and even the refusal of some health-care workers to care for patients. A paradoxical comfort and familiarity have set in because the diagnosis and treatment have become so common. A kind of routinization of available technical care has developed, but the systems to provide necessary comprehensive care are not ade-

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quately developed or they are faltering. At the beginning I could individualize each AIDS patient's care, but as the numbers have increased, knowing each patient with AIDS personally has become impossible. Gratifyingly, others have joined the ranks and teams of health-care workers now struggle with the myriad complex clinical and social issues that invariably characterize each case. But whatever is put into place is soon obsolete or inadequate. A self-selected core of physicians, nurses, social workers, community volunteers, and others have been drawn to AIDS as a primary professional activity, and many more when called have simply tried as best they could to do their jobs. Increasingly, there is the danger of resignation, futility, and burnout among those on the front lines.

There is a growing sense of anxiety about the future. Yet in the midst of it all and despite personal experience, uniform predictions for increasing numbers of cases, and calls for national and international mobilization,[19] personal, institutional, and societal disbelief persists and the fantasy of a quick and easy solution remains. Planning and provision of resources, particularly human resources, lag behind the pace of new cases. AIDS is now with us for the duration of human history, but this new and now permanent reality in our lives resists acceptance. "How many years do you think it will take to find a cure?" I'm asked repeatedly, rather than "How will we learn to live and manage with AIDS and HIV infection in our midst now and in the future?" Whether society, the health-care system, and health-care workers will effectively adjust to this new reality is unclear. For clinicians, fear of personal jeopardy, related to the risk of HIV transmission, the daily inescapable confrontation with death and dying, and the weariness engendered by overwork, hovers just below the surface. The fear breaks into full view periodically and unquestionably influences caregivers' daily function. Many, particularly those in training, rethink future professional plans. As I watch the caseload increase and the pressures on young doctors, nurses, and social workers mount, I wonder who will care for the huge number of AIDS patients in the future.

To understand the full complexity of medical-care issues confronting the clinician and health-care system, one must understand the clinical course of HIV infection and relate various stages to the array of health-care needs at each point. A familiar epidemiologic concept describes HIV infection or any infectious disease as a pyramid or an

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iceberg. The visible, symptomatic disease, in this case AIDS, represents only the tip above the surface. The bulk of infection lies below the surface, invisible but potentially of grave danger. Successive layers of increasingly healthy but infected individuals descend from the surface in an ever-widening base. To this epidemiologic image might be added a contiguous iceberg or a pyramid representing the need for clinical care and services. In this image the form is inverted, with the tip of need below the surface and the resource need widening as the illness grows more severe. Thus, although they may represent only a small fraction of people infected, the sickest patients require the greatest number of resources. As infection progresses over time, initially healthy infected individuals become sicker and resource needs increase. The hundreds of thousands of healthy infected individuals at the base of the pyramid now require minimal resources, but as they ascend to the iceberg tip, their care needs will widen beyond our resources.

It is essential to view HIV infection as a chronic viral illness progressing inexorably over time. Within weeks of acquiring HIV infection, a patient may develop a self-limited viral-like illness termed the acute retroviral syndrome.[20] Mostly unrecognized, it may require few resources. Infection then progresses to an asymptomatic stage with or without swollen lymph glands, which may persist for years, perhaps even decades. Technical medical care is usually not necessary, but if blood testing for HIV infection is performed, or if an individual perceives him- or herself to be at risk, severe psychologic symptoms may occur, including anxiety, depression, guilt, and fear of abandonment. In addition, loss of job or other forms of discrimination may occur. Minor medical problems are invariably interpreted as HIV related, and physician or clinic visits may result. Health-care providers must be available to assess clinical status, to counsel and educate about HIV transmission, and to effectively treat psychosocial problems and offer preventive medical services. Community-based organizations, if available, may be of great value here in providing support services.

Later, perhaps five or six years after the acquisition of HIV infection, clinical symptoms may appear. These may be vague and insidious or abrupt in onset, consisting of fevers, malaise, fatigue, weight loss, diarrhea, and skin and mucous-membrane infection. In addition to increased psychologic stress, technical medical needs

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begin to appear. Physician visits and occasional hospitalizations become necessary. Diagnosis and treatment of both HIV and complicating secondary infections begin. The need for outpatient and inpatient care is accompanied by diminishing independence and sometimes full disability with loss of employment or ability to perform usual function. Entitlements and arrangements for income, health care, and housing are often necessary.

The next stage in this continuum of infection is the onset of AIDS or more severe symptomatic HIV infection. This is associated with increasing hospitalization need and progressive debilitation. These have averaged 56 days per year per patient at our institution, or 25 percent of an individual's remaining life.[21] Neurologic dysfunction may occur in one-third of the patients and will progress to dementia in many. The array of complex, often invasive technical services for the treatment of infections, cancers, and neurologic complications widens. Home health services, including nursing care, homemaker services, and infusion of medications, may be necessary; and loss of job and housing often results in need for scarce long-term care facilities, and finally, if available, for hospice care. The ability to pay for health-care services or for supporting daily needs such as food and housing melts away as health and energy fail. Usually public facilities and resources, already strained and inadequate, are required.

Certainly in my work over the past twenty years, I've learned that there are other fearful diseases, but AIDS is clearly different and more difficult. Why are the care needs of patients and demands on health-care workers so extraordinary? The reasons are varied. Foremost among these is unquestionably *the nature of the disease itself.* AIDS is an excruciatingly cruel and relentless disease that is invariably fatal. Its repetitive onslaughts and the wasting, disfigurement, neurologic dysfunction, and disability it produces are disturbing. Gaunt, slow in movement, some breathless, others bedridden, AIDS patients increasingly populate the hospital landscape. I find myself looking at healthy young men and women who are well and functioning even after the initial AIDS diagnosis, and like a witness to an all too familiar drama, I see them in my mind's eye months or several years later wasted and suffering, shadows of their present selves.

Second, *the afflicted are mostly young*—men and women in the third and fourth decades of life—a time of productivity and achieve-

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ment or at least vigor. Although familiar in developing countries, in our society, death on this scale in this age group, except during a war, is something we are not accustomed to. The recurrent scenes of still young parents caring for their sick and debilitated young-adult or infant children and then burying them when they die is not one that fits our worldview. Death belongs to the old, not the young. AIDS causes an inversion of the expected life cycle. For health-care workers, particularly young doctors and nurses, this is especially difficult. Caring for dying young men and women of a similar age makes identification unavoidable and confrontation with their own mortality and vulnerability inescapable.

Third, all this is not a collection of isolated events but *an epidemic* of death and dying among the young. In areas like New York City, the numbers alone are both numbing and overwhelming. The experience is not one of an occasional dying young man with leukemia or a young woman mangled in an automobile accident. It is dozens and dozens of young men and women, in an increasing torrent over a very short period of time.

Fourth, there is a continuing *fear of transmission* among most members of our society, among health-care workers in particular. Although the risk to health-care workers is reassuringly low,[22] it is not zero. Measures exist to reduce the risk further, but there is no doubt that inadvertent, accidental injury may occur and cause infection. Made more frightening by being placed in daily contact with suffering people with HIV infection, this fear is constant among health-care workers, but mostly hidden.[23] It is essential to be sensitive to and understanding of health-care workers' fears and not to harshly condemn them. "To assume that health-care professionals need only a statistical appreciation of risk to assume the mantle of professional virtue in caring for AIDS patients is to deny their humanity."[24]

"I see something in the back of my throat and I'm sure it's thrush. I must have AIDS." A young intern accosted me in panic earlier this year. I examined him and explored his history. I was convinced it was a minor sore throat and not thrush, a throat infection characteristic of HIV, and that he was not at risk for and had not acquired AIDS, but it was impossible to dispel his panic. It was only after his HIV antibody test turned out to be negative two weeks later that he was able to resume functioning normally.

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Another young doctor appeared unexpectedly at my office early one morning: "I slashed my hand last night with a needle while I was doing a spinal tap on a woman with a history of IV drug use. I can't think straight. I couldn't sleep all night. What should I do? What should I tell my wife?" Although his test eventually turned out negative as well, it took months before he could definitely be told that he was not infected with HIV. He continued to work, but like so many others at risk, lived in fear until his final negative test result came back.

Paradoxically, I still see young doctors preferring to deny that they may be at risk and not wearing gloves as they draw blood from patients with AIDS. The flip side of their fear of infection is to deny it completely and thereby put themselves at greater risk. After seven years of working with AIDS patients, knowing well the minimal statistical risks, I must admit that I remain frightened. When I notice a blemish on my skin, I can't help wondering if it could be Kaposis sarcoma. I still interpret minor illness in myself as the beginning of the "expected" HIV infection although rationally I know better. The essential position for me and for other health-care workers is to recognize the fear but to act on the reassuring fact that the incidence of transmission is low. It is necessary to be sensitive and understanding of these fears among health-care workers, but we must be clear about our expectations in the AIDS epidemic. Although doctors have fled plagues in the past,[25] we cannot condone such behavior.

The risk of HIV acquisition is substantially less than for other infectious diseases such as tuberculosis, yellow fever, cholera, and plague. Further, we have the advantage of understanding routes of transmission, virology, and disease etiology. To deny or compromise the treatment of any patient on the ground that a medical risk is posed to the provider is to break the fundamental trust between patient and caregiver and between caregiver and society. Nevertheless, some have chosen not to give care. The difficulty is that the refusal is often subtle. It is passive and not overt and hard to identify. Mostly among some surgeons and others who perform "invasive" procedures, it takes the form of avoidance rather than refusal: "I don't think surgery—or a bronchoscopy—is necessary in this patient. Let's try antibiotics first and not operate."

Frustrating and difficult to combat, this behavior, in my experience, has been the exception and not the rule among most other

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health-care workers. Whereas for some health-care workers special risks may exist, these have not been documented and are not unique. Blood-bank and laboratory workers, obstetricians and midwives, interns and nurses are also exposed and for the most part have quietly and without complaint (although not without fear) done their jobs. In fact, although we concentrate on concern about health-care workers' refusal to care for AIDS patients, the predominant response is a remarkable story of personal and professional behavior of the highest standards. Tens of thousands of health-care workers—mostly young, vulnerable, and at the start of their careers—have faced the panic and their own personal discomfort and fears head on and have exemplified the very best in human and professional behavior. In many ways these are the unsung heroes and heroines of the AIDS epidemic.

AIDS is different from other diseases for a fifth reason. AIDS is deeply *rooted in our views of the social worth of individuals and the acceptability of behavior*. From the outset AIDS has been associated with illicit intimacy—it is a "dirty disease." For many, it remains a disease of homosexuals and intravenous drug users and is thereby bound to intimate behavior not felt to be acceptable. There is a related intolerance or at best unfamiliarity and lack of understanding of differences in race, ethnicity, and social class that characterize the present demography of AIDS. This view has been enhanced inadvertently by the designation of persons with AIDS into "risk groups." Although useful for epidemiologic surveillance purposes, this designation creates the illusion that nonmembership in an arbitrarily defined and seemingly homogenous group conveys protection. HIV transmission is the result of specific behaviors, not group identity. There is further belief that most of the infected have brought their illness on themselves and are therefore unworthy of compassion. It's a "blame the victim" mentality. Finally, there is a temptation to behave differently toward certain individuals with HIV infection than toward others. Infants, hemophiliacs, and transfusion recipients are characterized as "innocent victims" or "blameless," thereby implying that others infected with HIV are "guilty" and "blamable."

It is assumed that all those infected through drug use or sexual activity acquired infection willfully and knowingly. However, HIV was widely disseminated among homosexual men and intravenous drug users in the early 1980s before its existence was known. In addition, since those at risk are concerned about their health and

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future, many have reduced their risk of acquiring HIV. Motivated by fear of HIV acquisition, substantial reduction in risk behavior has been reported not only among homosexual men but also among intravenous drug users in recent years.[26] But even if this was not the case (and for the individual patient, it may not be) the issue of blame is irrelevant. So much of the illness we treat has its roots in behavior, and the behaviors that result in transmission of HIV are ubiquitous—sex and drug use. Sexually transmitted diseases have always been surrounded by disapproval and stigma, and intravenous drug use and its associated medical illnesses have received even greater reproach. Illicit intravenous drug use is criminal and results in serious health risks but in many respects is not dissimilar from alcohol abuse, cigarette smoking, and the abuse of diazepam (Valium) or other drugs we prescribe and administer.

Only a theoretical and abstract perspective makes blaming the victim easy. It is more difficult when one personally witnesses the suffering endured by AIDS patients and their loved ones and appreciates their courage in the face of this final adversity.

Most of the patients with AIDS treated at my institution have been intravenous drug users. They have the reputation of being difficult, frustrating patients. Engaged in an illegal activity, secretive in their behavior, and rarely having an established, ongoing relationship with a health-care provider, many intravenous drug users elicit disapproval from health-care workers and, in turn, are distrustful and expect judgmental treatment. I have found that when treated with attention to their medical needs in a straightforward, clinical manner, most intravenous drug users can be disarmingly open about their life-style and no more or less difficult than other patients. The essential point is that each person, intravenous drug user or otherwise, is unique and does not comfortably conform to a stereotype.

Instead of blaming the victim, it would be more constructive to examine the societal conditions that promote unhealthy risk-taking behavior and ask who is responsible for them. This is particularly true for intravenous drug use. It is not a matter of chance that rates of intravenous drug use are highest among poor minorities in the inner city. Illicit intravenous drug use is grounded in and the product of hopelessness. It is engrafted on unemployment, poverty, racism, and depression. Without doubt, it is perpetuated by greed and corruption at many levels in our society. It should be seen as a

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personal and societal symptom of deeper unaddressed ills. The final common pathway may lead to the intravenous drug user on the streets of the South Bronx and Harlem, but the genesis of drug use can be traced back through many levels of our society. Although certainly responsible for his or her own actions, the drug user is also the victim of powerful, disturbing, unconscionable social forces and conditions. In a sense, drug abuse heralds many of the unaddressed problems of this society, which have now come to haunt us in the form of the AIDS epidemic.

Intravenous drug use should be viewed as a medical and societal illness. It has remained refractory to efforts to eliminate it, which have largely been punitive and directed by law-enforcement agencies. Instead of insisting on cure or complete abstinence, we should seek reduction in the amount and frequency of drug use and advocate safer drug-use practices. A medical model of treatment should be our goal for all drug users. It remains a disturbing paradox that in the face of the AIDS epidemic we are able to provide specific treatment for no more than 10 percent of those actively using illicit drugs and we have been unwilling to mount programs that may make drug use safer.

Instead of blaming the victim, we would serve society better by talking openly about all risky behaviors, advocating broader and targeted education about the risks of unhealthy behavior, and providing treatment for those in need.

Finally, AIDS is different because *it forces us, particularly those of us who are physicians, to confront our own vulnerability and inability to substantially alter the power and force of natural events.* Trained during the decades since World War II and in the era of antibiotics and other interventions, most physicians believe that they can cure most diseases. Certainly they were taught to believe this in the field of infectious diseases, my own specialty. The administration of an appropriately chosen antibiotic could remarkably reverse the course of a virulent illness. A decade earlier while working in Africa, I learned that even with potent antibiotics, the social and environmental conditions that breed infection conspire to produce it again—that antibiotics are potent and magical but limited. We are now learning that lesson in this society as well. Most serious illness in our society is the result of chronic and not acute disease and is not amenable to seemingly magical technical interventions. Nevertheless,

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we still *believe* that the goal of our endeavors should be to cure and that anything less is failure. AIDS assaults this belief and this unrealistic goal and creates the uncomfortable feeling of inadequacy and failure in physicians. Although the goal of curing is of course paramount, the parallel ethic of prolonging life, improving the quality of life, and alleviating suffering is more realistic and appropriate. With these as goals, we can feel somewhat successful in treating most AIDS patients and people infected with HIV.

For those caring for AIDS patients during the past few years, substantial and gratifying progress has been made. A combination of scientific, clinical, and organizational expertise, as well as an intense commitment to work against AIDS and with persons with AIDS and HIV infection, has made this possible. HIV infection itself is now convincingly treatable with azidothimidine (AZT). This drug stands alone as the single proven effective agent in scientifically conducted clinical trials. Although there are substantial problems of toxicity and drug intolerance and the cost of AZT is prohibitive for many patients and societies, it has been a great advance for AIDS patients and their physicians. Experience with other potentially clinically promising agents unfortunately still remains limited. Clinical trials in progress are addressing the crucial issue of the effect of AZT on asymptomatic HIV infection, but no data are yet available. There is a sense of urgency about the pace at which we are acquiring new, useful therapies, and our frustration with it is understandable. Effective therapy for HIV infection and ensuing clinical illness, however, will be dependent on the development of potent and safe antiviral agents shown to be effective in scientifically rigorous trials.[27] For many physicians working with AIDS, the dual function of clinical investigator evaluating new therapies and physician caring for dying patients desperate for treatment creates tremendous dilemma and stress. Although the patients' welfare must always have priority, the goals and responsibilities of each role may often be in conflict.

At all stages of HIV infection, there is effective clinical treatment. Curative therapy is and will likely remain a distant and perhaps unachievable goal, but many of the clinical problems encountered in daily care are treatable. In many settings both the quality of life and the life expectancy of persons infected with HIV have been improved.[28]

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Effective therapies exist for most opportunistic infections complicating HIV infection.[29] Foremost among the treatable complications is *Pneumocystis carinii* pneumonia, the most common opportunistic infection in developed countries. (An opportunistic infection takes advantage of an already weakened immune system.) Important progress in both treatment and prevention of this infection has been made. Other protozoal infections, including toxoplasma encephalitis and isospora enteritis, are treatable, and recurrences of toxoplasmosis are also preventable.

Neurologic disease occupies a place perhaps second only to pneumocystis pneumonia in frequency and clinical consequence. Although the management of neurologic disorders is complicated, many opportunistic infections can be treated. Promising preliminary information suggests that AZT may alter the course of HIV-induced neurologic disease. The large array of pathogens infecting the gastrointestinal tract is an issue of particular importance in developing countries. Many of these infections are treatable as well. Bacterial infections complicating HIV infection have been recognized only recently, but many of these respond well to available therapies. Serious sight-threatening infections with the *cytomegalovirus*, until recently untreatable, are responsive to ganciclovir (DHPG), an experimental antiviral agent, although treatment regimens are difficult to carry out. Other complicating viral infections such as *herpesvirus* skin- and mucous-membrane infections respond easily to oral acyclovir. Mucosal surface candida infections are readily treatable with a variety of agents. Deeper tissue fungal infections caused by *cryptococci*, *histoplasma*, and others respond to treatment, although the only available drug, amphotericin, has substantial toxicity and requires intravenous administration. Therapeutic strategies for Kaposi's sarcoma and other malignancies associated with HIV infection have been elaborated. Although not curative, these strategies may offer patients some amelioration of clinical signs and symptoms and prolongation of life.

The next several years will likely bring forth additional welcome but complicated therapies, and clinicians may be confronted with a new problem—the need to learn, understand, and use the growing armamentarium of therapeutic agents whose indications, interactions, and toxicities have already formed a new body of knowledge. Many well-intentioned physicians avoid caring for AIDS patients

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because of unfamiliarity with currently available drugs and treatment strategies. Our development of new knowledge may outstrip our ability to assimilate, communicate, and use it appropriately on behalf of patients with AIDS.

In broader terms, these innovations and technical and clinical advances require delivery systems that can reach those in need and health-care professionals who can competently provide care. The provision of appropriate clinical care requires not just technical competence but a framework of comprehensiveness, continuity, and compassion. The components of this framework, the necessary ingredients for excellent care, are outlined in the table below but are difficult and often impossible to achieve. They require the development and coordination of comprehensive systems of care in the hospital, clinic, home, and community. In this clinical scheme, the patient and his or her family and loved ones, not the disease itself, should be the central focus and unit of care. Although essential for some HIV-induced illness, hospital-based, high-technology-oriented care is not always appropriate; it is prohibitively expensive for much

Table. Principles of Clinical Care for AIDS and HIV Infection

| |
|---|
| Focus on clinical care as well as cure. |
| Treat the patient and the family, not the disease. |
| Create a continuum of care in the hospital, the outpatient department, and the community. |
| Develop a multidisciplinary team and case-management approach. |
| Treat with antiretroviral agents when appropriate. |
| Prevent, diagnose, and treat opportunistic infections and other complications. |
| Provide support for environmental and special needs—income, nutrition, housing, drug-abuse treatment, health care, and legal services. |
| Help meet psychosocial needs—involve and support the family, loved ones, health-care professionals, and community groups. |
| Address issues of HIV transmission. |
| Protect confidentiality. |
| Be sensitive to issues of death and dying. |
| Support health-care workers. |
| Broaden care to educate and involve everyone in the health-care system. |

Adapted from G. H. Friedland, "Clinical Treatment of AIDS," *AIDS*, vol. 2, suppl. 1 (October 1988):S 133–35.

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of the clinical need of HIV-infected persons through most of the course of their illness. Systems of primary care, before and during debilitating illness, residential alternatives such as rent support, scattersite apartments or rooms, home health care, respite and adult day care, supported congregate facilities, long-term chronic institutional care, and hospice care are all needed. However, out-of-hospital systems of care and the trained health-care workers to staff them are lacking.

By virtue of the complexity of their needs, the clinical care of persons with AIDS and HIV infection tends to uncover all the flaws in the health-care system. Our system of care is not organized or prepared for an epidemic of a progressively debilitating, fatal illness in young men and women. Often the basic components of necessary care for persons infected with HIV, particularly outside the hospital environment, are absent or their relationship to one another so fragmented that they are unusable. In my own institution, 20 percent of the AIDS patients remain in the hospital unnecessarily because there are no long-term care facilities, no home care or housing available for them on discharge. Social workers spend most of their time trying to access and coordinate dysfunctional out-of-hospital systems of care. Some recent examples make these issues clear:

- Juan Santiago was diagnosed as an AIDS patient in September 1988. Suffering from severe diarrhea and wasting, he still managed to maintain a jaunty, proud facade. A former intravenous drug user who had last used drugs in 1984, he had just passed the exam for the police academy when he became ill. At thirty-five years of age, he had finally put his life in order before his diagnosis was made. Juan accepted that he was going to die and wanted to spend whatever time he had left at home with his two children and wife. She was five-months pregnant. When ready for discharge from the hospital, he needed intravenous infusion therapy at home for lengthy periods each day. Assistance was sought from a total of eight home health agencies to arrange for skilled nursing to provide the infusions. There was a shortage of nurses skilled in infusion procedures, and there was concern about the patient's insurance coverage and assurance of its payment. It took over two months for a home health agency to take his case. Juan remained in the hospital during this time, becoming progressively ill. His lack of health

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insurance delayed his treatment with AZT, and once he began to receive the drug, side effects made it impossible to continue its administration. I'm left with an image of him in his hospital room, standing at the side of the bed, emaciated, with hollow cheeks and clear, intense eyes, trying bravely but futilely to lift weights.

- Dolores Colon, although twenty-six years old and a mother of four children, has an ingenuous, childlike quality. She has AIDS and toxoplasmosis infection of the brain. She has responded well to treatment and returned home. Caring for Mrs. Colon has been complicated by her inability to comply with the care she needs. She has had three subsequent admissions to the hospital during the past year. Her most recent admission was preventable with simple medication, but she was unable to keep her clinic appointment because of several crises with her children. As their sole caretaker and supporter, her primary concern is that they be well cared for. Her own needs have been secondary. Although she is eligible for some limited home services, she has not sought such help. She is overwhelmed and not able to acknowledge the implications of her disease. She was the sexual partner of an intravenous drug user who is the father of her youngest child. Having intermittently and unsuccessfully sought treatment, he remains on drugs. Her husband insists on getting custody of the children, and she is afraid to deny them that although she knows that he can't care for them. She is afraid to inform her children of her diagnosis because she fears that they will inadvertently tell others and themselves become stigmatized. She should be receiving AZT and aerosolized pentamidine, but she has not been able to keep appointments to receive treatments or comply with their administration.

These cases are not atypical. They illustrate the context in which AIDS occurs and must be treated. To address this complex illness requires both technical medical as well as psychologic and environmental support. Some innovative models of clinical care based on relatively separate and distinct structures and personnel for AIDS care have been developed. In other models new personnel and resources have been added in areas where the ability to meet the care needs of AIDS patients has been completely absent, and existing resources have been strengthened and coordinated where present but

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inadequate for the complete care of persons with AIDS. For most environments, the creation of a new system of care is neither feasible nor desirable, and a more appropriate approach is to strengthen and rationalize existing structures and to spread the care broadly throughout the system. The creation of completely separate structures for AIDS care may result in the reduction of personnel and resources for other essential programs and may thus weaken the entire system and ultimately the AIDS effort as well. A central core of expertise in the comprehensive care of persons with AIDS is necessary, but all health-care workers should learn to participate in the diagnosis, treatment, and management of the clinical-care needs of HIV-infected patients, particularly in areas of high prevalence.

Even if all health-care workers do participate, the inequities and uncoordinated irrational aspects of the health-care system, characterized by a patchwork quilt of programs, fiscal requirements, and unresponsive institutions, will work only if there is equity throughout the system. Equity may in turn require nothing short of a national health-care system.[30]

The major impediment to AIDS clinical care in the future is likely to be the unavailability of sufficient numbers of health-care workers to provide the necessary services. Thus, one of the most urgent needs is attracting, training, supporting, and retaining health-care workers to provide clinical care.[31] The impact of AIDS on health-care manpower cannot be exaggerated. Who will provide clinical care for AIDS patients? HIV infection and AIDS are extraordinarily labor-intensive illnesses through all stages and in all health-care settings. High technology has a relatively minor role in the total care of patients over the course of their illness. AIDS-specialized physicians are few in number and still occupy a poorly defined place within the profession. Coming from other medical specialties such as infectious diseases and oncology, they are neither fully equipped nor trained to provide for the comprehensive needs of AIDS patients. The delivery of ongoing primary care is not a feature of infectious-disease practice. Yet, by virtue of their expertise, the care of AIDS patients has often fallen to them. Tension between traditional infectious-disease specialists, particularly in academic centers, and those committing themselves to AIDS work has often developed. AIDS represents an unwelcome intrusion into the usual consultative function of infectious disease specialists, untrained or unable to accommodate

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primary-care responsibilities into their daily schedules. Conversely, generalists in medicine and pediatrics are more closely trained in the AIDS-care paradigm of comprehensiveness and continuity but do not presently have the special expertise to handle the complex problems and medications required by many sick AIDS patients.[32] There will not be enough AIDS specialists, and reliance on provision of care by primary-care physicians rather than AIDS specialists will be essential, particularly in areas of high prevalence of HIV infection. Relevant, intensive programs of AIDS education for physicians are necessary, beginning in medical school and extending to those already in practice who must provide care. The difficulty of attracting new physicians to AIDS care is compounded by an already declining interest in the primary medical specialties such as internal medicine and pediatrics, which antedates the AIDS epidemic. The allure of higher paying, less demanding, high-technology specialties such as radiology and anesthesiology is difficult to counter. Provision of primary medical care must be made more attractive if sufficient physician resources are to be available.

The situation is even more serious in the nursing profession.[33] Absolutely crucial to the care of AIDS patients both in and outside the hospital, nurses are underpaid, inadequately respected, undervalued as professionals, and dwindling in numbers as AIDS needs increase. Social workers must be added to this list of undervalued, underpaid, yet desperately needed professionals who are in short supply. Skilled at providing psychologic and environmental support for patients and viewing the family as the unit of care, social workers often function as the essential links between unconnected vital services and entitlements, and provide psychological support for both patient and family. In the AIDS-care model at my institution, social workers are at the center as case managers and patient advocates. Home health aides provide additional essential services yet are rewarded with job insecurity, no health coverage, and minimal salaries.[34] How can we expect to attract needed newcomers into AIDS work if the prospect for each is stress, overwork, and low pay?

Solutions for these health manpower needs will require creativity, commitment, and resources. The system of care in which these needs arise must be supportive of the care providers. Long hours, stress, and exhaustion are not conducive to personal safety, compassion, and care, or even to competence. Health-care workers' compassion for

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AIDS patients will last only within a framework of competence in a system that provides both necessary resources and an appropriate environment for care.[35] In such a setting, individual acts of competence and compassion can flourish. Without this support, those caring for AIDS patients will be physically and emotionally overwhelmed, and clinical competence and acts of compassion will wither or care providers will go elsewhere.

Teaching about AIDS early in students' professional education will demystify the disease and remove ignorance and fear. Basic curricula in the education programs of all medical and health professions should be modified to ensure adequate training in HIV infection and AIDS care.[36] Provision of scholarships for primary care and AIDS work may attract new recruits. Appropriate salaries and improved benefits and job flexibility may help attract and retain nurses. Home health-care workers could be recruited and trained from high-unemployment inner-city youth by creating the equivalent of a civilian conservation corps, simultaneously providing care and reducing unemployment. Family members who must leave the houses of AIDS patients to work at marginal jobs to provide income could be reimbursed for providing care in their own homes.

Health-care workers are exposed to increasing psychologic and emotional strain from working with AIDS patients and, to provide care, must maintain their own health. Programs for support of beleaguered workers are essential but scarce. Staff burnout can be countered by establishing flexible work schedules, rotating responsibilities, and setting up mechanisms for group support.

It would be inaccurate and misleading to convey the impression that working with AIDS has only negative aspects for health-care workers. Indeed, for the health-care professional armed with increasing expertise and appropriate resources, care of persons infected with HIV and AIDS can provide great opportunities and rewards. Foremost among these is leaving behind what is by comparison unimportant. In my own experience, participation in the clinical, scientific, emotional, and personal challenges of these early years of the AIDS epidemic has been sufficient reward. My colleagues and I have learned to use new therapies and therapeutic strategies, participated in multidisciplinary care, and made scientific inquiries and discoveries. We have learned again about the basic value of teaching and communicating—with patients, families, colleagues, students, the

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public, and ourselves; about setting priorities and gaining perspective; about remarkable human courage and love in the face of unimaginable adversity and suffering; and about helping to forge international bonds in the worldwide effort against AIDS.

Finally, it must be said that the very populations in need of clinical strategies, dedication, and expertise are the ones with least access to them. AIDS disproportionately affects populations in which health-care resources and manpower are in scarce supply both in developing countries and in industrialized countries among intravenous drug users and others living in poverty. The prohibitive cost of AZT and the absence of a delivery system to reach those who may benefit is a case in point. How can societies such as Zaire and Uganda, whose gross national products are $127 and $240 per capita respectively, afford to provide AZT at $8,000 per patient per year? How can New York City afford to provide this drug to the estimated 200,000 HIV-infected persons, half of whom are poor intravenous drug users? How can the city put in place the systems to deliver it? What will motivate our entire society, which has been unable or unwilling to extend adequate health care to those in poverty in inner-city areas, to do so now under the added stress of the AIDS epidemic?

In geographic areas with high prevalence of HIV infection, concern is appropriately growing that the existing health-care system will collapse under the weight of the AIDS epidemic.[37] This crisis, however, carries along with it great opportunity. Were adequate resources provided and their deployment redirected to out-of-hospital care and prevention, the development of effective technical clinical-care strategies and efforts to efficiently and humanely organize their delivery might not only preserve but improve the entire health-care enterprise. The lessons learned in caring for AIDS patients, the principles and systems of care developed in the AIDS epidemic, would greatly benefit patients with other illnesses and indeed all of society.

First we must accept the reality that AIDS is here to stay and that hoping it will go away or expecting that we have the ability to remove it are both products of wishful thinking. Then we must demonstrate the political and societal will to provide what is needed. Although it will not have been worth the suffering, at least AIDS will strengthen our health-care system and our society, and we may be able to

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conclude that "what we learn in a time of pestilence is that there are more things to admire in men than to despise."[38]

ENDNOTES

I am indebted to countless patients and their families and loved ones, who at a time of great adversity have brought me closest to what is essential: courage, humility, and doing what needs to be done. I am grateful to my colleagues at Montefiore Medical Center for their dedication, competence, support, and generosity of spirit and to Ms. Lucy Carrion for her expert secretarial assistance.

[1]From Albert Camus, *The Plague*, trans. Stuart Gilbert (New York: Alfred A. Knopf, 1983).

[2]F. Barre-Sinoussi, J. C. Chermann, F. Rey, et al., "Isolation of a T-Lymphotropic Retrovirus from a Patient at Risk for the Acquired Immunodeficiency Syndrome (AIDS)," *Science* 220 (4599) (1983):868–71; and R. Gallo, S. Z. Salahuddin, and M. Popovic, "Frequent Detection and Isolation of Cytopathic Retroviruses (HTLVIII) from Patients with AIDS and at Risk for AIDS," *Science* 224 (April 1984):500–503.

[3]G. H. Friedland and R. S. Klein, "Transmission of the Human Immunodeficiency Virus," *New England Journal of Medicine* 317 (October 1987):1125–35.

[4]Centers for Disease Control, "Human Immunodeficiency Virus Infection in the United States: A Review of Current Knowledge," *Morbidity and Mortality Weekly Report* 36 (1987):5–6.

[5]Centers for Disease Control, "Classification System for Human T-Lymphotropic-Associated Virus Infections," *Morbidity and Mortality Weekly Report* 35 (1986): 334–39.

[6]A. Glatt, K. Chirgwin, and S. Landesman, "Treatment of Infections Associated with Human Immunodeficiency Virus," *New England Journal of Medicine* 318 (June 1988):1439–48; and S. Broder and A. Fauci, "Progress in Drug Therapies for HIV Infection," *Public Health Reports* 225 (May–June 1988):224–28.

[7]Institute of Medicine and National Academy of Sciences, *Confronting AIDS, Directions for Public Health, Health-Care and Research* (Washington, D.C.: National Academy Press, 1986); and Institute of Medicine and National Academy of Sciences, *Confronting AIDS, Update 1988* (Washington, D.C.: National Academy Press, 1988).

[8]*Assuring Care of New York City AIDS Population* (New York: Mayor's Task Force on AIDS, September 1988); *New York City Strategic Plan for AIDS* (New York: Interagency Task Force on AIDS, May 1988); *Report of the Presidential Commission on the Human Immunodeficiency Virus Epidemic* (Washington, D.C., June 1988); and P. Piot, F. Plummer, and F. Mhala, "AIDS: An International Perspective," *Science* 239 (February 1988):573–79.

[9]AIDS Surveillance Unit, *AIDS Surveillance Update* (New York: New York City Department of Health, 28 September 1988).

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[10]AIDS Program, *AIDS Weekly Surveillance Report* (Atlanta, Ga.: Centers for Disease Control, September 1988).

[11]J. M. Mann, J. Chin, P. Piot, and T. Quinn, "The International Epidemiology of AIDS," *Scientific American* 259 (4) (October 1988):82–89.

[12]Ibid.

[13]B. R. Saltzman, G. H. Friedland, R. S. Klein, J. Vileno, K. Freeman, and L. K. Schrager, "Factors that Predict Survival of AIDS Patients, Experience at a Single New York City Medical Center," Fourth International Conference on AIDS, Stockholm, June 1988.

[14]N. A. Hessol, G. W. Rutherford, A. R. Lifson, P. M. O'Malley, L. S. Doll, W. W. Darrow, H. W. Jaffe, and D. Werdegar, "The Natural History of HIV Infection in a Cohort of Homosexual Men: A Decade of Followup," Fourth International Conference on AIDS, Stockholm, June 1988.

[15]*New York City Strategic Plan for AIDS.*

[16]*Assuring Care of New York City AIDS Population.*

[17]M. Alderman, E. Drucker, A. Rosenfield, and C. Healton, "Predicting the Future of the AIDS Epidemic and Its Consequences for the Health Care System of New York City," *Bulletin of the New York Academy of Medicine* 14 (March 1988): 175–83.

[18]*New York City Strategic Plan for AIDS.*

[19]*Confronting AIDS, Directions for Public Health, Health Care and Research*; *Confronting AIDS, Update 1988*; *Report of the Presidential Commission on the Human Immunodeficiency Virus Epidemic*; and Mann, Chin, Piot and Quinn.

[20]"Classification System for Human T-Lymphotropic-Associated Virus Infections."

[21]Alderman, Drucker, Rosenfield, and Healton.

[22]Friedland and Klein; and "Recommendations for Prevention of HIV Transmission in Health-Care Settings," *Morbidity and Mortality Weekly Report* 36 (2S) (1987):3S-18S.

[23]R. N. Link, A. R. Feingold, M. H. Charap, K. Freeman, and S. P. Shelov, "Concerns of Medical and Pediatric House Officers About Acquiring AIDS from their Patients," *American Journal of Public Health* 78 (April 1988):455–59.

[24]*Update 1988.*

[25]A. Zuger and S. H. Miles, "Physicians, AIDS, and Occupational Risk: Historic Traditions and Ethical Obligations," *Journal of the American Medical Association* 258 (October 1987):14; and J. K. Kim, and J. R. Perfect, "To Help the Sick: A Historical and Ethical Essay Concerning the Refusal to Care for Patients with AIDS," *American Journal of Medicine* 84 (January 1988):135–38.

[26]P. S. Selwyn, C. Feiner, C. Cox, S. Lipshultz, and R. Cohen, "Knowledge About AIDS and High Risk Behavior Among IV Drug Users in New York," *AIDS* 1 (October 1987):247–54.

[27]R. Macklin and G. H. Friedland, "Drug Research on AIDS: An Ethical Analysis," *Law, Medicine, and Health-Care* 14 (December 1986):273–81.

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[28]G. H. Friedland, "Clinical Treatment of AIDS," *AIDS*, vol. 2, suppl. 1 (October 1988):S133–35.

[29]Ibid.; and Glatt, Chirgwin, and Landesman.

[30]R. L. Dickman, A. B. Ford, J. Liebman, S. Milligan, and A. L.Schorr, "An End to Patchwork Reform of Health Care," *New England Journal of Medicine* 317 (October 1987):1086–88.

[31]Deborah Cotton, "The Impact of AIDS on the Medical Care System," *Journal of the American Medical Association* 260 (July 1988):519–23.

[32]D. W. Northfelt, R. A. Hayward, and M. F. Shapiro, "The Acquired Immunodeficiency Syndrome Is a Primary Care Disease," *Annals of Internal Medicine* 109 (November 1988):773–75.

[33]J. K. Inglehart, "Health Policy Report, Problems Facing the Nursing Profession," *New England Journal of Medicine* 317 (September 1987):646–52.

[34]Mary Jane Koren, "Home Care—Who Cares," *New England Journal of Medicine* 314 (April 1986):917–920.

[35]G. H. Friedland, "AIDS and Compassion," *Journal of the American Medical Association* 259 (May 1988):2898–99.

[36]*Directions for Public Health, Health Care and Research.*

[37]Alderman, Drucker, Rosenfield, and Healton; and D. S. Weinberg and H. W. Murray, "Coping with AIDS: The Special Problems of New York City," *New England Journal of Medicine* 317 (December 1987):1469–73.

[38]Camus.

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*Peter Phoenix*

# Alive with AIDS

ONE DAY ABOUT TWO AND A HALF YEARS AGO I was driving home late in the evening from a particularly long and complex working day when I suddenly had a sharp pain in my abdomen. I thought it was gas, but it didn't go away, and when I got home it got worse. By taxi my wife and I went to the hospital, where my doctor met us. It turned out that I had an inflamed appendix. It had to be removed that same night.

The surgery was not very complicated or serious, but I didn't recover well. I had fever, weakness, swollen lymph nodes, and I couldn't eat much. A few days after I went home, my doctor asked me if I wanted to be tested for AIDS. I had shared with him previously that I had had a brief homosexual affair some years before.

I readily agreed to the test, sure that it would come out negative and relieve me of a nagging worry. It took about three weeks for the result to come back. By that time, I had recovered from the operation, but the test came out positive.

I was given this news on the telephone—not, I must point out, the best way—and left on my own to react. I told my wife right away, but I'm not sure either of us appreciated what it meant.

I remember that it seemed unfortunate but not tragic. A positive virus test didn't mean I was going to get the disease, at least not right

*The man who calls himself Peter Phoenix in this article is a health professional in his late fifties who finds himself in a struggle against AIDS.*

*This piece is dedicated to all AIDS patients everywhere, in the hope that it will give them a little courage.*



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away, and maybe not for years and years. I didn't think I had to do anything about it.

In nearly thirty-five years of marriage, we had never faced a life-threatening illness. We had had some serious problems through the years dealing with some of the strains in the relationship. Once or twice we had thought about separating, but unlike many of our friends we never did. In recent years I had come to realize clearly that I loved and respected my wife, and that I was lucky to have her. I regretted my sexual adventures of a few years ago and sincerely hoped and believed that they were in the past. Now, it seemed, they were coming back to attack us.

I stayed well for eight or nine months, and when the weather turned warm and pleasant we went off on our annual vacation to our summer cottage in the country, a place I love very much. While there, I became ill with a series of minor afflictions—virus with fever, shingles, cough, weakness. We had a seriously flawed vacation, and I feared I would have difficulty driving home, but I managed.

That fall I was well except for a chronic cough. In midwinter we went to the Caribbean for a week, and I was fine. When we got back, however, I became seriously ill with high fever and difficulty breathing. I was found to have pneumonia, not due to pneumocystis that time, and I spent ten days in the hospital.

It took me several months to recover. In the summer my pneumonia returned full force, and this time it was pneumocystis. I spent twenty-two days in the hospital and had a close brush with death. Today I am on my feet once more, working full-time, dealing with family, friends, clients, and colleagues, and even finding the capacity to enjoy some of the pleasures of life.

In the words of my doctor, I have been on "an emotional roller coaster." Most days I feel hopeful, optimistic, determined to stay well and function well as long as possible. But I have days when I am so depressed that I can barely get out of bed and my major activity is planning my funeral. Fortunately, the depression isn't often this extreme. I have had to learn not to share these black moods with my wife, because it is unfair to her. Her emotional task in dealing with the illness is almost as difficult as mine.

I asked my doctor to refer me to an AIDS specialist for a consultation, and in this way I first met the members of the AIDS team in the hospital, who have taken care of me since. At the head of

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the team is a doctor who is both an expert on AIDS and a good human being. From him I have learned that the practice of medicine consists of much more than tests, pills, injections, and surgery. He is interested not only in my medical condition but in how I live and how I feel.

Almost equally important are the other doctors, the nurses, and the social workers. I got to know most of them during my most recent hospitalization. They provide empathy as well as counseling and nursing care. Together they seem almost like a family to me. It is good to know that I have people who will help me and with whom I can share the feelings that come with the illness.

## SECRECY

I didn't want my friends and colleagues to know I had AIDS. Many people know little about the disease and are fearful of those who have it. Homosexual activity and intravenous drug use are the most common ways of getting it, and most people don't want these activities publicly known. This desire adds to the need for secrecy.

I have some friends who have had heart attacks and whose health situation is scarcely better than mine. Heart disease is believed to result from stress, eating too much cholesterol, and smoking, activities which, while not admirable, don't have to be concealed. AIDS patients are in a very different position.

In my case, the only people who know are my family, my doctors, my therapist, and a few very close friends. If others knew, they would probably be sympathetic but I would be uncomfortable. I don't feel that I'll tell anyone else.

That is why this piece is written under a pseudonym and why I have made some minor changes in the facts intended to conceal my identity.

I would like to describe the most important things that have helped me deal successfully with the illness up to this point.

## THE BEST MEDICAL CARE

I am fortunate to be in the health-care profession, so that I have knowledge of where the best medical care is to be found and the financial resources to make it available. I am the beneficiary of the

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expert judgment of physicians who are experienced and knowledgeable in the management of the illness and its complications. This feeling of confidence in my doctor and his associates is one thing that keeps me going.

There are of course some things that not even good medical care can do, aside from the obvious fact that no one has discovered a way to cure the infection. The doctors know how to treat the major complications like pneumocystis, and I am getting treatment to prevent its recurrence and also to prevent tuberculosis. But AIDS sufferers have a host of minor complaints that are not life threatening but which make life unpleasant, at times unbearable. In my case they include an itchy chest wall resulting from the attack of shingles I had two summers ago, itchy feet from a fungus infection that won't respond to local treatment and won't go away, oral and esophageal thrush, warts on the face, and maybe more to come. My doctors are sympathetic, but in many cases there isn't much they can do. (Thrush, I must add, can be treated effectively.)

There have been dramatic moments. At one point when I was critically ill with pneumocystis and required high levels of oxygen to survive, my doctor asked me what I would want him to do if I should require an endotracheal tube and be placed on a mechanical respirator. Such a tube and respirator would keep me alive, but I might never be able to get rid of them and I would suffer a long and painful death. On the other hand, they might keep me alive until my lungs recovered, if they could, and my life would be saved. The alternative would be to simply let me go. Which would I prefer?

I was terrified by the question, but after a few minutes I said that if there were any chance at all at life I wanted to take it. He told me he felt I had made a life-affirming decision. I believe this confirmed his view of me as a courageous person and a fighter. This helped me think of myself the same way.

## PSYCHOTHERAPY

I believe in the usefulness of therapy, and in this situation I sought it for myself. I spent about a year in a support group for people with AIDS or fear of AIDS. I joined the group not long after receiving my first positive test. There were six men, all younger than I, and mostly homosexual. A few had had positive tests, but most had not been

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tested but feared they had AIDS because of their life-styles. Dealing with this fear was the main focus of the group. It proved to be very supportive for me, particularly because of the acceptance and sympathy I experienced from the other members. I also got to like and respect the therapist. The group ended in June, when people went away on vacation, and did not reconvene in the fall.

Later, when things got physically worse for me, I went to the same therapist for individual therapy. My therapist has worked a great deal with AIDS patients and knows a lot about the illness. He is warm and has real empathy for me and my plight. He uses a variety of techniques, such as role playing and visualization. His support has been invaluable. With his help I have been able to deal with issues I have avoided in several previous therapies.

An example is the way he helped me deal with my ambivalence about sharing feelings with my wife. I needed my wife's love and support, but I couldn't bring myself to unload on her all the fear, grief, and anger that I was feeling. I didn't want to alienate her or cause her pain.

My therapist set up a pillow on a chair and said, "Let this be your wife." He had me tell her, in this safe and protected situation, all the things that I was afraid or reluctant to say in real life. I poured out my feelings. He interjected a few comments, playing her role as best he could.

Later, at home, I was able to say a few simple and nonhurtful things that made me feel closer to her, and she was able to respond. Since then, I have felt much less conflicted.

## FAMILY SUPPORT

I have two adult children and a son-in-law. My son, who is gay, has a long-term partner who has turned out to be just as much a part of the family support system as any of the others. It took me about a year after I learned of the positive test before I was able to tell any family member other than my wife. This was a problem for her as well because it deprived her of anyone who could provide her emotional support (I had my therapist). When we were able to tell the children, they took it hard but immediately rallied.

It was due to my son that I started to use AL-721, a substance developed in Israel for the management of AIDS. It consists of a

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mixture of fatty substances that are supposed to coat the surface of the cell and prevent attachment of the virus particles. No claim is made that it cures the disease, but it is said to be capable of controlling the progress of the disease for long periods of time. The FDA has not approved it, primarily because of the difficulty of doing the necessary research studies.

My son found out how to obtain it in England. Unknown to me, he flew there, picked up a two-month supply, brought it home, and put it in my freezer (it has to be kept frozen). Both my wife and I were incredibly moved, and I immediately started taking it. I have found several other ways to obtain it, and I still take it. My doctor has approved my using it.

The other family members have been equally devoted, and this realization has meant much to me. They all visit and call frequently. We have many cheerful family gatherings in which there is little talk of illness unless new developments make it necessary. But I have no doubt of everyone's support and good feeling.

## DEALING WITH DEPRESSION

Depressive feelings are perhaps the most difficult part of the illness. I should point out that depression and I are not strangers. For most of my adult life I have had a tendency to become depressed from time to time, and sometimes I have required treatment for it. Before this, it has always gone away after a while, or I have learned to handle it, and it has eventually been replaced by the mood of hope and optimism, which is my more usual state. This time it's not so easy.

I have given suicide some serious thought, even wondering whether it is a rational option. If I die soon, my loss will be felt by many people. But if I kill myself, I will be seen as having given up, and I don't want to be remembered that way.

When I get depressed, I try to find someone to talk to. My therapist is the best person. He doesn't blame me for being depressed, and he doesn't try to talk me out of it. I don't feel I am hurting him by sharing my depression, as I have felt with my wife. I generally feel better after talking to him. He knows enough to realize that he can't take the burden away from me, but he seems to be saying, "If you need someone to be sympathetic, to understand your feelings and help you feel not so alone in your situation, I'm here for you."

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If it isn't possible to talk to him, I try to distract myself by getting busy with something unrelated to my illness. Books, television, and music have all served this purpose. When I'm very depressed, only television will do, as it is the only activity that stops me from thinking and feeling.

### MEDITATION

My therapist has taught me the elements of meditation, and I have learned more by reading and by practice. I now meditate several times a week. It leaves me relaxed and optimistic.

My technique has been developed from several different sources, including trial and error. I meditate in a quiet place, either lying on a bed or sitting in a relaxed position. I use a series of steps producing focused attention and profound physical relaxation.

When I have achieved the necessary relaxed and attentive state, I use a series of visualizations in which I picture the damaged T4 cells of my immune system mobilizing themselves and defeating the virus particles in my bloodstream. Whether this helps my immune system I don't know, but I am still here and functioning.

### THOUGHTS ABOUT DEATH—AND LIFE

Everybody dies in the end, a fact most people would rather not consider. When I found out I had AIDS, I began to think a lot more about dying, and I believe I have begun to lose my fear of it.

Please don't misunderstand this. I have no wish to die, and in fact in arranging my affairs I have told my doctors that I want to stay alive as long as possible. But I know I will die in the end, as we all will, and when the time comes I feel I will have the strength to accept it.

I have never believed that death is real. It has always seemed to me that the human spirit survives. I was raised in a religious home but have not been very observant as an adult. It is hard for me to accept the doctrines and dogmas of any organized religion. But I have always been a believer, not just since being ill. One of the things I do is talk to God. It is difficult to describe this, but there is no doubt that it is a source of comfort and strength.

My feet itch, my chest itches, I have warts on my face, and my weight is ten pounds below what it ought to be. I have no energy, my

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legs don't work right, I am subject to periodic depressions, and my friends and colleagues don't know what is wrong with me.

But I am alive, working every day, enjoying the closeness of a loving wife and family. I do not feel like a dead or a dying man. I feel very much alive.

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*Daniel M. Fox, Patricia Day, and Rudolf Klein*

# The Power of Professionalism: Policies for AIDS in Britain, Sweden, and the United States

THE RESPONSE TO THE EPIDEMIC of human immunodeficiency virus infection and related diseases reveals similarities as well as differences in the policy systems of the three countries we examined for this paper—Britain, Sweden, and the United States.[1] Both the incidence and therefore the financial and emotional impact of the HIV epidemic have been considerably greater in the United States than in either Britain or Sweden. Moreover, familiar differences in the political cultures of the three countries influence the making of health policy. The politics of health, for instance, is considerably more acrimonious in the United States than in Britain or Sweden.[2] Nevertheless, in late 1988, the health policies of all three countries defined AIDS primarily as a professional problem in the management of what was increasingly seen as a chronic condition.

As a professional issue, the epidemic was mainly a problem for experts in clinical medicine, research, and public health and was, by and large, an unseemly subject for partisan debate. In each country, some people emphasized moral and emotional issues in the epidemic.

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But even in the United States, where these groups have been loudest and occasionally effective, policies have been made mainly in response to the opinions of the customary actors in health affairs. Policy for the AIDS epidemic was no more an issue in the American presidential campaign in the fall of 1988 than it was in the Swedish election campaign in the summer or in the rhetoric of the British political parties during their annual conferences. Moreover, in all three countries, despite their very different approaches to balancing individual rights and social obligations, protecting the right to privacy of individuals with HIV infection was, for both practical and ideological reasons, assumed to be a central purpose of policy. The protection of confidentiality, even anonymity, had become a technical aspect of public-health practice.

This interpretation of how three countries have responded to the epidemic may appear to be naive about the wisdom of experts and insensitive to the profound tensions and conflicts about what is proper policy. Two limitations on our story must therefore be noted. First, we do not attempt to evaluate the effectiveness of the policy responses in each country, either compared with each other or against some idealized standard. Second, we are not presenting a social history of the reaction to the epidemic in the three countries but concentrating exclusively on the policy responses.

Our story has three themes:

1. The initial government reaction to AIDS in all three countries was slow and cautious, even dilatory in the eyes of some.

2. Once government (national government in Britain, both the federal government and that of some states in the U.S.A., and the central government, the county governments, and municipal governments in Sweden) decided to take strong initiative, it quickly established the terms of debate. Governments pursued AIDS policies modeled on historical responses to outbreaks of plague and other virulent infections.

3. Policy in the three countries has, in the main, been based on consensus, both professional and political: a consensus that has ruled out certain options (like widespread mandated screening for infection) but that has also generated considerable support for the course pursued. In particular, policy has rested on agreement that the

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epidemic, whatever its unique features and however menacing it might appear, is a disease like any other as far as research and treatment is concerned. The consensus has evoked dissent in all three countries. But in all three, governments have employed their standard procedures for hearing, acknowledging, and to a very limited extent, accommodating the dissenters.

First we summarize central issues in the history of policy responses to the epidemic in Britain, Sweden, and the United States. Then we draw some conclusions about what this history suggests about the adequacy of the three policy systems for dealing with unexpected epidemiological threats.

## BRITAIN

AIDS was first diagnosed in Britain toward the end of 1981. The scale of the epidemic remained small for some time. By the end of 1983, 29 cases had been reported, and by the end of 1985, 271. Mid-1988 statistics show a cumulative total of 1,800 cases. Cases are reported on a voluntary and confidential basis to the Communicable Disease Surveillance Centre. At last count, some 9,000 positive tests had also been reported to the organization, although estimates of the total number infected range from 19,250 to 48,200.[3]

AIDS in Britain is largely a phenomenon of London and Edinburgh and their hinterlands. Over half of all reported AIDS cases have been concentrated in three inner London health districts. The distribution of cases by patients' characteristics is also skewed. A full 83 percent involves homosexual or bisexual men. The second largest category, 8 percent, involves recipients of blood products. Among those with HIV positive tests, the distribution is the same, with one important exception—Scotland, where intravenous drug abusers are the largest category of all. Moreover, women and children account for 28 percent of seropositives in Scotland but for only 6 percent of known AIDS cases in the rest of the country.

The turning point in public policy toward AIDS came in 1986. Before then, the Department of Health relied on established services and existing public-health routines. Circulars were sent out to the medical profession. The discovery that infection could be transmitted through blood led, first, to an appeal to high-risk groups not to

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become donors and, following the availability of the ELISA test, to the screening of all blood donations. The provisions of the 1984 Public Health (Control of Disease) Act were extended to cover AIDS—including a provision that permits patients to be compulsorily hospitalized—but were never activated following an unsuccessful test case. The task was left, however, to the civil servants and technicians of the department, in particular to Sir Donald Acheson, the chief medical officer, who was required, in the words of one of his colleagues, to "batter his head against a brick wall" of indifference among ministers who "tended to have complicated feelings about homosexuality."

Then came 1986 and a rush of activity. Ministers set up a cabinet committee and initiated parliamentary discussions of AIDS. Generous funding for research and the management of persons with AIDS by health authorities started to flow. The Government launched a public-education campaign, unprecedented in its scale and its frankness about sexual habits.

Why 1986? A number of complementary explanations offer themselves. First, there was increasing evidence that an epidemic previously confined to deviant minorities might be spilling over into the population at large. Second, there was the visit of Britain's secretary of state for health, Norman Fowler, to the United States, where he saw the impact of the epidemic for himself. Third, there was the fact that within the department there was a strong public-health lobby, headed by Acheson, pressing for action. Fourth, a series of lurid AIDS stories in the tabloids prodded ministers into taking an interest. Fifth, the Government's dawning interest in turn presented an opportunity for a variety of lobbies to press their case to the ministers—for example, the research community and the medical staffs of the Clinics for Sexually Transmitted Diseases. The gay lobby was less visible in Britain than in the United States, perhaps because it had fairly easy access to the department. Lastly, the secretary of state may have seen, in the rising salience of AIDS, an opportunity to wring extra cash for the National Health Service out of the Treasury.

In all this, the Government was intent on creating and maintaining political consensus. In November 1986, it initiated the first House of Commons debate on AIDS. The debate provided an impressive picture of Britain's politicians establishing a consensus within which future policy was to be made. This consensus rested on the repudi-

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ation of the view that AIDS could be seen as a "gay plague," a belief that the solution lay in changing the entire population's sexual behavior through public education and a rejection of measures such as compulsory testing, which might threaten civil liberties as well as be ineffective.

The consensus was sealed by the 1987 report of the all-party Social Services Committee of the House of Commons. Just as Government policy itself was shaped by the public-health model, articulated within the Department of Health by Acheson, so the committee's report was shaped by three doctors it recruited as its advisory staff for the inquiry. While giving its blessing to the consensual professional approach of public policy, the committee added a quasi-theological gloss: AIDS, its report concluded, had "highlighted things that are wrong with our society" and provided a "focus to try to remedy such problems." In short, the problems of AIDS had become opportunities for those seeking new arguments for pushing old causes, whether the advocacy of chastity or the pressure for more research funding.[4]

The Government's subsequent strategies reflect the consensus forged in 1986 and 1987. The most conspicuous of these—unique to Britain perhaps in its scale and outspokenness—has been the education drive. For the first time, a British government launched a national media campaign to change the sexual behavior of the population. Its message was: if you cannot cut down the number of your partners, use condoms. The strategy has been as much to raise general awareness as to target the message exclusively to high-risk groups, although drug users were picked out for special attention. This strategy avoided stigmatizing the homosexual community, the education of which was largely left to voluntary organizations like the Terrence Higgins Trust. But it is not known as yet whether public education has changed heterosexual behavior. There is a strong case for the community as a whole to change sexual behavior in order to limit the future spread of AIDS; however, the incentives for heterosexual individuals to change their behavior are weaker given the risk factors known at present.

From the start of the epidemic, policy for the treatment of AIDS has been shaped by the assumption that the existing services of the National Health Service provide the means for managing the disease, that there is nothing special about AIDS except for the extra demands on resources. In practice, therefore, the management of care has been

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left to clinicians. But the Department of Health has made large-scale extra grants to health authorities in the worst affected parts of the country. Such disease-specific grants are against precedent. To some extent, Britain has joined Sweden and parts of the United States in making AIDS an exception to established rules about financing health care.

The same pattern is evident in the case of research—reliance, at first, on normal organizations' routines followed by an injection of extra funds. Until 1986, AIDS research had to compete against other fields at a time of much complaint in Britain's scientific community about dwindling funds. By 1987, the Medical Research Council had made just eight special grants for AIDS research. But in 1986 the cabinet committee sanctioned spending on an ambitious program of AIDS research submitted by the MRC and designed to develop a vaccine and antiviral drugs. AIDS then became a source of extra money for the scientific community.

The only instance of AIDS overriding established policy objectives has been in the field of drugs. The risk that AIDS might spread into the heterosexual population through drug takers led, early on, to the Department of Health providing funds for drug-misuse agencies to expand their activities. Experimental needle-exchange schemes were extended and made permanent in 1988. The Government had abandoned its previous stance of augmenting its restrictive and punitive policies on drugs now that AIDS had come to be seen as the greater danger.

Nevertheless, AIDS has not been seen as justifying any dilution of traditional libertarian or professional values in Britain. Ministers, the medical profession, and the homosexual communities appear to be united in resisting demands for compulsory screening programs and in insisting on both confidentiality in testing and on making testing conditional on the availability of counseling. The position of the medical profession—as articulated both by the General Medical Council (the regulatory body) and the British Medical Association—has been a key factor in giving priority to the doctor-patient relationship rather than to epidemiological information. Even the announcement of the anonymous testing of routine blood samples in the autumn of 1988 caused rumbles and, in contrast to Sweden, there is no systematic contact tracing of the kind used to control other sexually transmitted diseases.

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The combined weight of Government and professional pronouncements—backed by all political parties—has thus made overt discrimination socially unacceptable. This is not to claim that there is no discrimination. Because it is defined as unacceptable, its occurrence is not monitored systematically. For example, the Department of Employment condemns discriminatory practices at work, but there are no legal provisions (except suit for wrongful dismissal) to back its exhortations. Similarly, people at high risk of illness, whether AIDS or high blood pressure, have difficulty in getting life insurance and therefore home mortgages.

Overall, AIDS in Britain is emerging as a long-term health policy problem rather than a dramatic moral or social crisis. From being seen primarily as a condition to be treated in the acute medical services, AIDS is being perceived as requiring care mainly outside hospitals. The disease will be testing Britain's health services at their weakest point, which is coping with chronic disease in the community.

Increasingly too, it is being realized that any spread in the heterosexual population may be slower than had been anticipated.[5] The latest predictions suggest that the future may be less scarifying than expected. There is a paradox at the heart of Britain's consensus. In order to mobilize support for their policies, in particular policy designed to change sexual mores, politicians have dramatized the epidemic. If AIDS comes to be seen as just another routine killer disease like cancer or coronary disease, professionals and Government will lose one of the few weapons they have for the mobilization of support: fear.

## SWEDEN

The first cases of AIDS in Sweden were diagnosed late in 1982. The annual incidence grew slowly; 6 cases in 1983; 10 in 1984; 30 in 1985; 49 in 1986; 64 in 1987. By mid-1988, just under 200 cases had been reported, 80 percent of them in gay and bisexual men. Approximately 2,000 people had been diagnosed as infected with HIV (of almost half a million tested) though some independent estimates put the number as high as 5,000 or even 10,000.[6] As the number of cases grew, medical and lay leaders of a few gay organizations and a handful of other doctors and epidemiologists called attention to the

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threat posed by the disease. Responding to their concerns, the national press regularly covered the growth of the epidemic, particularly in the United States.

There was, however, disagreement about the extent of the threat to Sweden. In 1983, when a leading Stockholm academic specialist in infectious disease wrote a newspaper article about the spreading epidemic, he was criticized for exaggeration by a group of gay doctors.[7] The doctors who have treated most of the persons with AIDS in Stockholm since 1983 recalled in 1988 that as late as 1985 their chiefs denied their requests for additional staff and space for treatment. A gay physician who is now the president of a prominent voluntary organization providing services to persons with HIV infection said that in the early years of the epidemic, "authorities here as in the United States . . . tried to cover big needs but without great generosity."

Since 1985, the central government has asserted its considerable authority in making AIDS policy. In September of that year, the cabinet classified AIDS as a venereal disease under the Prevention of Infectious Diseases Act. Under this act a "person who suspects that he may be suffering from a venereal disease is bound to seek medical attention." Patients are tested anonymously. Anyone who is infected must, however, be identified in the medical record, though names are not submitted to public-health authorities. Doctors initiate contact tracing, which is conducted mainly by social workers. The act also provides sanctions against patients who refuse to cooperate, but to date the sanctions have been used in only a few cases.[8]

Provision for treating persons with AIDS also increased rapidly after 1985. Doctors at Roslagstull Hospital, the infectious disease division of the Karolinska Institute, were authorized to open a unit for outpatient treatment in June of that year. At that time two and a half doctors, three nurses, and a secretary provided treatment for 500 outpatients and inpatients with HIV infection and related diseases. By 1988, seven doctors, six nurses, three social workers, and two secretaries were serving 600 patients.

The rapid expansion of treatment programs after 1985 was a result of the pressure of officials in the central government on county authorities and reluctant members of the academic medical hierarchy. A change of leadership in the hierarchy of academic internal medicine, particularly in the specialty of infectious disease in Stock-

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holm in about 1985, appears to have been both a cause and an effect of this pressure. Another ingredient was the growing consensus among leaders of both the ruling Social Democratic Party and the opposition parties that the epidemic required more active policy, especially to prevent heterosexual transmission of the virus. A few leaders of the opposition considered using AIDS as an example of the deficiencies of Prime Minister Eric Carlsson and of Minister of Health and Social Affairs Gertrud Sigurdsen. Attacks on Sigurdsen began in 1985 and accelerated in 1987. She was accused of underestimating the number of seropositives and being overoptimistic about controlling the epidemic. Opposition leaders wrote newspaper columns or gave interviews attacking government policy for not giving HIV infection sufficient priority. The doctor in charge of the AIDS treatment unit at Roslagstull wrote a newspaper article advocating more resources for treatment; he recalls that his budget was quickly increased.

The prime minister and the minister for health and social affairs responded to this political threat by creating a formal body of about twenty members to advise the government on policy. The members included Social Democratic and opposition politicians, civil servants and interest-group leaders. The Swedish name of this body, the AIDS-delegationen, is usually translated into English as National Commission on AIDS. But Swedish officials insist that it has never behaved as a typical government commission, which customarily meets in closed sessions and then issues a report. The AIDS-delegation (as we will translate it) is, according to a senior official, "unique . . . [and] its constitutional role unclear." Even the principal secretary of the AIDS-delegation agreed that it was "not a very typical way" of making policy in Sweden. Similarly, the chairman of the parliamentary committee on health and social affairs, when asked for a parallel to the AIDS-delegation, of which he is a prominent member, said "probably something like it was created during a cholera epidemic in the last century."

The conventional Swedish system for achieving consensus on policy was in disarray as officials, politicians, doctors, and interest-group leaders grappled with AIDS in 1985. The debate over amending the Prevention of Infectious Diseases Act had been uncommonly divisive. Gay organizations bitterly opposed classifying AIDS as a sexually transmitted disease. Feminist groups were troubled by what

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they regarded as threats to the civil liberties of prostitutes in the amendments. Moreover, there was criticism in the press of the government's public information policy—its emphasis on the risk of heterosexual spread and its relative blandness in comparison with campaigns in Britain and some cities in the United States. AIDS was also causing increasing debate about the government's policy for controlling drug use. Members of county councils were worrying about the costs of treating persons with AIDS. National politicians in the opposition parties were testing the viability of challenging the government on AIDS policy.

The AIDS-delegation was a forum for reestablishing consensus. Its original members represented the National Board of Health and Social Welfare, the national bacteriological laboratory, the association of county councils, the national federation of local authorities, the two largest of the five political parties, and medical experts. "When you have these, you have everybody in Swedish society," its principal secretary said. A few months later, the government redefined *everybody* to include the other three parties.

The AIDS-delegation moved quickly to shape consensus. The members agreed unanimously that AIDS should be regulated as a sexually transmitted disease. They agreed on the necessity of contact tracing and that routine testing, with informed consent, was a good policy for clinics treating infectious and venereal disease and pregnant women. Although "every member of the delegation knows" that doctors are illegally preserving the anonymity of some people who test positive, there was consensus to ignore the problem because "we're trying to encourage people to be tested."

Consensus has been difficult to achieve on two subjects: the intensity of public-education campaigns and policy to control the transmission of HIV infection among intravenous drug users. Some members of the delegation believe that AIDS education has exceeded the attention span of most members of the general public, that "people are tired of hearing about it."[9] Others sympathized with a staff member who quit in December 1987 because the delegation's information campaigns were insufficiently aggressive.

Considerable conflict remains about policy for controlling HIV infection among intravenous drug users and their sexual partners. The reason for the conflict, according to a senior civil servant, is that the policy dilemmas in this area are "too difficult politically" to

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engage. When the conflict became public in 1985, Sweden had vigorous policies to control the supply of narcotic drugs and provide drug-free treatment. In 1985, ministry officials proposed, and the AIDS-delegation endorsed, a policy goal of treating all intravenous drug users. Over the next two years, local government expenditures for drug treatment more than doubled. "AIDS meant that now local government was taking the official goal seriously," the civil servant recalled.

There is still controversy over methadone maintenance and needle-exchange programs, but consensus is emerging. Under pressure from doctors and voluntary association leaders whose primary concern is AIDS, the ministry has reluctantly agreed to double Sweden's modest methadone maintenance program to 300 places. Similarly, officials opposed establishing needle exchanges because the "message will be too schizophrenic." Nevertheless, a doctor at a university clinic in Lund established a program that has had favorable publicity, considerable local support, and the endorsement of the chairman of the all-party parliamentary committee on health and social welfare. Officials of the National Board of Health and Social Welfare reluctantly admit that exchanges "will be hard to resist."

Many gay leaders who have been critical of government policy are active in the quasi-official Noah's Ark Red Cross Foundation. Noah's Ark mounts programs of education, offers counseling and support services, and is establishing a guest-house, hospice, hot-line, and reception service.[10] Its budget, guaranteed by the Swedish Red Cross, is being financed this year by grants from the national government and from the Stockholm municipal and county authorities. Its president, a prominent gay doctor, supports, with reservations, government policies for controlling the epidemic. In the last year, he says, "powerful people have stopped doing as little as they could." But he worries that there is still considerable denial of the extent of the epidemic, reflected in official underestimation of the number of people who are infected and resist needle exchanges.[11]

Some muted dissent remains. A few academic doctors have worried in public that AIDS is deflecting funds from other priorities. When Astra, the largest Swedish drug manufacturer, withdrew from research related to HIV earlier this year, the prime minister embarrassed its managers by telling the International Congress on AIDS in

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Stockholm that pharmaceutical companies have moral as well as commercial responsibilities.

During the first few years of the epidemic, Swedish officials were cautious, like their counterparts in Britain and the United States. A few critics accused them of ignoring a potentially devastating problem, others of being unnecessarily alarmist. Beginning in 1985, the central government organized a coalition to establish the epidemic as a classic public-health problem requiring case finding, education, and treatment. Achieving consensus became an important goal, both because consensus is central to Swedish political culture and because less dissent is tolerable in a classic public-health response to an epidemic than during political business as usual. The AIDS-delegation, a new political device, was the instrument for achieving the symbolism and much of the substance of consensus. Only in the area of policy for drug treatment was there disarray; but in mid-1988 there was evidence that a consensus was emerging.

## UNITED STATES

The scale of the epidemic is greater in the United States than in either Britain or Sweden. As this paper was being written, almost 70,000 cases had been reported in the United States since 1981, whereas in Britain 1,700 had been reported and in Sweden only 200. Estimates of the number of people infected ranged from 500,000 to 1.5 million.[12] The cumulative incidence in the United States (237.7 per million) was an order of magnitude greater than in Britain (which had an incidence of 25.2 per million) and in Sweden (21.5).

Most accounts of the epidemic in the United States create a superficial impression that AIDS policy in the United States has been characterized more by conflict than by consensus. These accounts emphasize disputes about screening, testing, needle exchanges, drug research, and treatment.[13] Since about 1985, however, policy for the epidemic has been made mainly by the same professionals, supported by the same coalitions, nationally and in the states, that have dominated health affairs for half a century. The disagreements about policy that remain appear to be more intense than similar controversies in Britain or Sweden do, in large part because the public rhetorical dramas of symbolic politics are a mechanism for coping with the fragmentation of political authority in the United States.

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When the AIDS epidemic began, the American health polity was changing more rapidly than it had in a generation. The individuals and institutions that had dominated health affairs were poorly prepared to take aggressive action against an infectious disease that was linked in the majority of cases to individual behavior, was expensive to study and treat, and required a coordinated array of public and personal health services. The epidemic of HIV infection began in a political climate characterized by what appeared to be a fundamental shift in the locus of authority for health policy from the federal government to state governments and the private sector and in the willingness of public officials to let doctors and scientists continue to control spending with minimal oversight. Moreover, the strength of right-wing pressure groups seemed to preclude sympathetic policies for a disease that was most prevalent among homosexual men and intravenous drug users and that afflicted a disproportionate number of blacks and Hispanics.

In the early 1980s, many people criticized the Reagan administration for not mounting a conventional public-health attack on the epidemic. The critics included some officials of state and local government, a few influential members of Congress, leaders of gay-rights organizations, and several high-ranking officials of the agencies that comprise the United States Public Health Service.[14]

These critics had considerable evidence. The Reagan administration was, until 1986, reluctant to request funds from Congress for research on and services for dealing with the epidemic. Right-wing members of Congress blocked proposals to spend federal funds for education to prevent AIDS on the ground that abstinence, from both sexual relations and drug use, was the only appropriate message. Leaders of major gay-rights organizations criticized the surveillance guidelines of the federal Centers for Disease Control (CDC), which coordinated data collection nationally and strongly influenced policies in the states. They feared that policies that promised confidentiality rather than anonymity, or that required contact tracing (euphemized as partner notification), would drive underground many persons at risk and generate resistance to pleas to practice safer sex and use clean needles. Health-insurance executives and hospital administrators complained to the press and to legislative committees that the cost of treating persons with AIDS was a heavy burden that was made worse by the absence of federal subsidies.

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Although there is still considerable dispute about priorities in the United States, as there is in Britain and Sweden, policy for the epidemic is being made mainly by experts in clinical medicine, research, and public health. The triumph of professionalism at the federal level was symbolized by the advocacy, from 1986 on, of vigorous federal action to combat the epidemic by C. Everett Koop, surgeon general of the Public Health Service. Koop had been appointed in 1981 on the basis of right-wing credentials. Now he insisted that his responsibilities as a doctor and a public-health official took precedence over his religious beliefs about sexuality. He has been warmly supported by officials of the Public Health Service, by members and staffs of key congressional committees, and in general by the press.

The same experts who dominate other arenas of health policy are now leading the response to AIDS. Two reports by the Institute of Medicine of the National Academy of Sciences gave advice that is often cited as guidance for proper policy by officials of the federal government and most of the states. The President's Commission on the HIV Epidemic, after a politicized false start, submitted a report that was widely praised by the media and by leaders of clinical medicine, research, and public health.

After an acrimonious beginning, biomedical scientists have resumed their conventional public stance of international cooperation and pride in the rapidity of the advance of knowledge. Robert Gallo of the National Institutes of Health and Luc Montagnier of the Pasteur Institute publicly resolved their acrimonious conflict over who had first discovered the virus responsible for AIDS. Clinical trials of potential drug treatments for HIV-related diseases are proceeding at more than thirty institutions, funded by the NIH and supervised by a committee of principal investigators. The Food and Drug Administration has promised to expedite approval of new drugs.

Controversies over surveillance policy have been contained. A few states (nine by early 1988) mandate confidential reporting of the names of seropositive individuals. Partner-notification programs of varying types are in place in every state.[15] Officials of state and local government and leaders of gay-rights organizations less frequently question CDC recommendations and policies in public. A bitter debate between CDC staff and social scientists in other agencies and outside government over how to measure the incidence of HIV

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infection—indeed, about whether accurate research is even possible—has largely been conducted in private.

The content of mass education campaigns is increasingly left to experts. At the urging of Surgeon General Koop, the federal government mailed an informational pamphlet to every household. In the summer of 1988, conservative senators and representatives ended their resistance to using federal funds for education about avoiding infection.

Disputes about how much it costs to treat persons with AIDS have subsided. By 1986, there was evidence that the early estimates of the cost of treatment were unnecessarily alarmist.[16] In 1987, Congress responded to testimony about the high cost of AZT, the first moderately effective therapy for some persons with AIDS, with an appropriation to the states to subsidize purchase of the drug. Federal officials encouraged states to seek waivers of Medicaid regulations to permit them to pay for noninstitutional services for persons with AIDS. In the fall of 1988, Congress authorized additional funds to treat AIDS.

Physicians became increasingly prominent advocates for making out-of-hospital services available for persons with HIV infection. A few physicians began specializing in managing HIV infection, especially in the metropolitan areas with the highest incidence of the disease and growing numbers of infected persons. Many of these specialists direct hospital units for persons with AIDS and coordinate out-of-hospital services through case managers who are paid by public and by insurance and foundation funds. These physicians collaborate with public-health officials and with leaders of voluntary organizations that provide support services for persons with HIV infection to press for more resources for testing, laboratory work, nursing homes, and hospice care.

In 1988, federal funds for programs to treat and study intravenous drug addicts were substantially increased for the first time in a decade. The politics of drug treatment and of law enforcement are now in conflict, however. Needle exchanges have been proposed in several states, but most police officials and prosecutors oppose them.

The history of the AIDS Institute of the New York State Department of Health exemplifies the reassertion of the authority of conventional medical and public-health leaders in policy-making for HIV infection. After its creation by legislative initiative in 1984, the

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institute was led by a social worker who had previously directed the New York City voluntary organization the Gay Men's Health Crisis. His principal associates were planners, social scientists, and health administrators—some of them gay, none of them physicians. Both the budget of the institute and its dominance by medicine have grown in the past two years. Although that budget continues to finance a network of community-based organizations that provide support services and to sponsor educational programs, the main activities of the AIDS Institute are financing and coordinating testing programs and hospital-based AIDS treatment centers.

In the United States, particularly in New York City and San Francisco, the crisis of authority in health affairs in the early 1980s and the concern about AIDS among gay men, many of whom were politically sophisticated, permitted new players to have considerable influence for a time on health policy. This influence appears to be waning, in part as a result of the death of some leaders from AIDS and the exhaustion of others, partly as a result of increasing incidence of the disease among drug users, but mainly because of the restoration of the traditional sources of authority in health affairs—however fragmented they may be in the United States in comparison with those in Britain and Sweden.

Neither presidential candidate made AIDS an issue in 1988, perhaps because sex, homosexuality, and drug abuse were divisive issues in a campaign that already involved uncommon hostility. But both candidates committed themselves to maintaining the surveillance, research, and financing policies now in place: there was little new for them to say—certainly no sound bites for television.

The national political consensus also reflected broad agreement about policy (and who was in charge of it) in the states with the highest incidence of the disease. For example, an initiative on the 1988 ballot in California that would have sanctioned considerable discrimination against persons with HIV infection was defeated by more than two to one after being opposed by public-health officials and the leading organizations of health professionals.

Despite the vastly different scale of the epidemic, the history of policy in the United States resembles, in broad outline, events in Britain and Sweden. The federal government and most of the states acted cautiously (too slowly, critics said) during the early years of the epidemic. Since 1985 and especially 1986, however, the federal

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government and many of the states have become more active in setting policy for the epidemic, relying on experts for advice. At the same time, the fragmentation of American government—by jurisdiction, by competing interests and experts—and the strong impact of moral and emotional issues—especially in local and state affairs—have added tension to the consensus.

## CONCLUSIONS

In all three countries, policy has been made mainly on the basis of the advice of experts after political leaders in central government (and in several American states) have decided to take the initiative. Moreover, especially since 1985 and 1986, policy in each country has been based on a broad consensus from which there is, as yet, politically ineffective dissent. In all three, interest groups in health affairs have used the epidemic as an opportunity to press for additional resources for AIDS research and prevention and for treatment of drug addiction. Moreover, in all three countries, though with considerably more acrimony in the United States, the institutions that finance health services have accepted the obligation to pay the unanticipated costs of caring for persons with AIDS.

Leaders of organizations of homosexual men have behaved with similar ambivalence in all three countries. On the one hand, they have insisted on positive discrimination: the allocation of additional resources to prevent, treat, and study AIDS. On the other, they have sought to avoid discrimination that could enhance stigmatization. As a result, they have at times emphasized the extent of the danger of HIV to gay men and, at other times, either minimized the threat to their own communities or universalized the epidemic as a threat to heterosexuals.

There are also important differences in the politics of the epidemic and therefore the policy responses to it among the three countries. In the United States, alone of the three, the epidemic is strongly linked to poverty and race. The British have given priority to education and innovative drug programs. The Swedes have emphasized traditional forms of prevention—testing and contact tracing—and have greater confidence than the British or Americans that the people handling data about seropositivity will maintain the privacy of individuals.

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Americans, as they have since the 1940s, find it easier to reach consensus on policy for research than on financing health care.

The policies of all three countries in 1988 are evidence of the authority that medical, scientific, and public-health professionals have acquired during this century, especially since the 1940s. In all three countries, AIDS has been defined as a classic public-health crisis, a temporary threat requiring special policies selected from the repertoire of professionals. As AIDS becomes a chronic problem, however—as it comes to resemble tuberculosis in the nineteenth century or any of the many chronic diseases today—the classic public-health policy model may become less appropriate.

If AIDS turns out to be just another killer disease, governments may no longer be able to use fear to justify the allocation of additional resources to study, prevent, and treat it. AIDS already resembles a chronic disease or a severe disability because of its claims on long-term care as well as acute services and its relatively high cost per case. New treatments that increase survival time after infection would make it even more obviously a chronic problem; so would a slowing in the rate of incidence.

Yet AIDS is unlike the leading chronic diseases that provide the epidemiological context for contemporary health policy. It is not a disease of the middle and later years of life. The behaviors that lead to most of the cases evoke little sympathy, much less than overeating, drinking alcoholic beverages, and even smoking do. In the absence of the fear of rapid heterosexual transmission that currently sustains the classic public-health model of response to this epidemic, it may be difficult for experts to continue to make policy by consensus. And if the consensus breaks up because the sense of urgency that has sustained it evaporates, persons with HIV infection may be more at risk of being stigmatized under a chronic-disease model of policy than they are at present.

AIDS raises questions about fundamental values, most of which have, up to now, been transposed into debates among professionals about how to allocate scarce resources. During the past century, experts and public officials devised highly effective methods for restating questions about values as problems of technology and information. To date, policies for AIDS in the three countries we have studied offer many examples of the triumph of the ethic of professionalism over the confused and conflicting claims of morality and

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ideology. Given uncertainty, it has suited everyone to leave AIDS, like most areas of policy, to the professionals.

ENDNOTES

[1]We are grateful to many people in the three countries who spoke with us both on and off the record. Our generalizations are based on these conversations as well as a review of newspapers, magazines, pamphlets, and public documents, which we do not cite here.

[2]Our generalizations about political culture and the politics of health care are amplified in Daniel M. Fox, *Health Policies, Health Politics: The British and American Experience, 1911-1965* (Princeton: Princeton University Press, 1986) and in Rudolf Klein, *The Politics of the National Health Service* (London: Longman, 1983 and 1989). For a recent comparative analysis of Sweden, see Christopher Ham, "Governing the Health Sector: Power and Policy Making in the English and Swedish Health Services," *Milbank Quarterly* 66 (2) (1988): 389–414.

[3]Sir David Cox, chairman, *Short-term Prediction of HIV Infection and AIDS in England and Wales: Report of a Working Group* (London: Her Majesty's Stationery Office, 1988).

[4]House of Commons Social Services Committee, *Problems Associated with AIDS*, Session 1986–87 (London: Her Majesty's Stationery Office, 1987), House of Commons, 182–1. See also the Government's response: Department of Health and Social Security, *Problems Associated with AIDS* (London: Her Majesty's Stationery Office, 1988), Cm. 297.

[5]Cox.

[6]National Swedish Board of Health and Welfare, *HIV and AIDS in Care: An Analytical Survey for the Health Care and Medical Services* (Stockholm: Socialstyrelsen, 1988). See also David Finer, "The HIV/AIDS Situation in Sweden," *Current Sweden*, no. 364 (June 1988).

[7]National Swedish Board of Health and Welfare, *This is What the Law Says about HIV and AIDS* (Stockholm: Socialstyrelsen, 1987).

[8]*Stockholms Tidningen*, 17 April 1983, 32.

[9]Bengt Brorsson and Claes Herlitz, in "The AIDS Epidemic in Sweden: Changes in Awareness, Attitudes and Behavior," unpublished paper, Swedish Medical Research Council, July 1987, reporting results of three mail surveys, conclude that "changes in awareness, attitudes and beliefs have accelerated since the start in March, 1987 of the Swedish AIDS information campaign."

[10]Noah's Ark Red Cross Foundation, *An Organization Against HIV and AIDS* (Stockholm: Stiftelsen Noaks Ark-Roeda korset, 1988).

[11]For a dissenting view, see Benny Henriksson, *Social Democracy or Societal Control: A Critical Analysis of Swedish AIDS Policy* (Stockholm: Institute for Social Policy–Glacio Bokfoerlag, 1988).

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[12]For a recent summary, see William L. Heyward and James W. Curran, "The Epidemiology of AIDS in the U.S.," *Scientific American* 259 (4) (1988): 72–81.

[13]For a bibliography of leading accounts to 1988 as well as sources for much of what follows, see Daniel M. Fox, "AIDS and the American Health Polity: The History and Prospects of a Crisis of Authority," in Elizabeth Fee and Daniel M. Fox, eds., *AIDS: The Burdens of History* (Berkeley: University of California Press, 1988), a revised version of an article published in *Milbank Quarterly* 64 (suppl. 1) (1986): 7–33.

[14]The best account of events within CDC and the Public Health Service in the early 1980s is Elizabeth W. Etheridge, "The Believers: A History of the CDC," unpublished manuscript, Centers for Disease Control, 1988.

[15]Various publications of the Intergovernmental Health Project of George Washington University report state law and regulation concerning AIDS. On contact tracing, see Centers for Disease Control, "Partner Notification for Preventing Human Immunodeficiency Virus Infection—Colorado, Idaho, South Carolina, Virginia," *Morbidity and Mortality Weekly Report* 37 (25) (1988), reprinted in the *Journal of the American Medical Association* 260 (5) (1988): 613–15.

[16]Daniel M. Fox and Emily H. Thomas, "AIDS Cost Analysis and Social Policy," *Law, Medicine and Health Care* 15 (4) (1987–1988): 186–211. For papers on the cost of the epidemic, see Daniel M. Fox and Emily H. Thomas, *Financing Care for Persons with AIDS: The First Studies, 1985–1988* (Frederick, Md.: University Publishing Group, 1989).

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*Nicholas A. Christakis*

# Responding to a Pandemic: International Interests in AIDS Control

WHILE *EPIDEMIC* AND *PANDEMIC* BOTH denote diseases that simultaneously attack many members of a community at a rate greater than normal, the two differ in that the latter occurs over an extensive portion of the planet. AIDS is a pandemic. Unlike other so-called international health problems, such as malaria and smallpox, AIDS strikes the developing and developed world with equal vengeance and forces all nations to consider their common interests in the solution of international health problems. The AIDS pandemic provides a new opportunity to view health as an international phenomenon, one that is best addressed by policies with international dimensions.

According to World Health Organization (WHO) estimates, based on cumulative reports from 133 countries through February of 1988, the world has had 150,000 cases of AIDS and between 5 million and 10 million people are presently infected with HIV, the causative organism.[1] While Asia and Oceania have thus far largely been spared, Europe, Africa, North America, and South America have all been significantly affected. The United States and central Africa have been the hardest hit—forming two epicenters of the pandemic—with 204 reported cases of AIDS per million inhabitants in the United States and about 150 cases per million in central Africa.[2] Estimates of the prevalence of HIV infection in the general population range from

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0.04 to 0.3 percent in the United States[3] and from 0.7 to 18 percent in certain central African countries.[4] Preliminary evaluation of the effect of such infection rates in developing countries suggests that AIDS is so serious a threat that it may substantially reduce their population growth rates over the next few decades.[5] In response to this worldwide threat, more than 77 nations have tried to confront the problem unilaterally by passing laws regarding AIDS.[6]

That AIDS is found and addressed unilaterally in most countries around the world, however, does not make AIDS an international problem per se. The common cold exists in every country of the world, but it is not ordinarily perceived as an international problem. There is a distinction between a *worldwide* problem and an *international* problem. The latter has an important feature in addition to worldwide occurrence. This feature is the direct interrelatedness of the problem in one country with the problem in another or of the cause of the problem in one country with the effect in another. Such interrelatedness is typical of a number of problems in the world today, including pollution, ozone depletion, arms proliferation, hunger, and AIDS. International interests in AIDS control arise largely because of this interrelatedness.

The AIDS problem meets the interrelatedness criterion on several levels. First and most obvious, the disease is caused by an organism that does not stop at national boundaries. The spread of HIV within a country is related to the spread of infection throughout the world because HIV is transmitted through human contact. Though intrinsically more deadly and less explosive in its spread, HIV is in this respect similar to the influenza virus, another cause of pandemic disease.[7]

The movement of the virus across international boundaries is paralleled by the movement of medical ideas, care providers, and investigators. Western and Western-trained medical investigators and health-care workers have increased their attention to medical problems in the developing world over the past few decades. Despite the appeal and prominence of non-Western medical systems, Western biomedicine has become the only truly international system of medicine. One aspect of the ascendancy of Western biomedicine is the increasing role international organizations play in health care. Aid organizations and pharmaceutical firms deliver Western-based health-care services and Western medicines the world over. Con-

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fronting the AIDS pandemic will thus involve the systematic use of the same general medical system throughout the world.[8] Insofar as the parts of this international medical system are interrelated, the parts of the global AIDS problem which this system confronts will meet the interrelatedness criterion.

Beyond the nature of the virus and the state of contemporary medical practice, AIDS is an international problem because of the nature of health. The AIDS pandemic, as we shall see, suggests that we take an ecological view of health, a view that stresses the interrelatedness of the health of people throughout the world.

The identification of AIDS as an international health problem raises a series of important questions. Is an international response to the AIDS pandemic required? If so, which aspects of the global AIDS problem should receive international attention? What are the national and international interests in AIDS control? What are the obstacles to international cooperation in the control of AIDS?

## NATIONAL AND INTERNATIONAL INTERESTS IN AIDS CONTROL

Every nation has an interest in AIDS control because it has a stake in the health of its citizens. Virtually all those infected with HIV are now thought to develop AIDS, a disease for which the mean survival is presently about two years, even in developed countries. As a major cause of both sickness and death, AIDS brings about serious suffering and psychological distress. Nations have a rational interest in the limitation of such adverse effects on the physical and mental well-being of their citizens.

AIDS presents monetary costs that nations also have good reason to want to limit. One well-informed estimate of the direct costs of care of AIDS patients in the United States in 1986, for example, is $1.1 billion; this is expected to rise to $8.5 billion in 1991.[9] Direct nonpersonal costs (for research, screening, education, etc.) are estimated at $0.54 billion in 1986 and $2.3 billion in 1991. Indirect costs (attributable to the loss of productivity due to AIDS morbidity and mortality) are estimated to have been $17 billion in 1986 and $55.6 billion in 1991. The direct costs for 1991 represent 1.4 percent of estimated personal health-care expenditures for all illnesses; and the indirect costs in 1991 represent 12 percent of the indirect costs of all

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illnesses. From a monetary perspective, confronting the AIDS problem by limiting the spread of infection or developing less expensive or more effective treatment protocols is therefore a significant interest of the United States and other nations.

Nations have an interest in AIDS control beyond the health threat AIDS poses and the cost it engenders. A number of features of AIDS as a disease—its lethality, its sexual transmission, and its appearance in previously stigmatized or neglected groups—have made it a threat to the social structure of society. AIDS has raised troubling questions regarding sexual behavior, privacy rights, discrimination, and professional responsibility. In nations around the world, AIDS has been problematic for the insurance industry, blood-bank services, the military, the penal system, and the school system.

Such health, monetary, and social issues are present in all nations but differ in each nation according to its cultural, political, and medical features. The differences are most evident in a comparison between developed and developing countries. The social impact of AIDS clearly varies. For example, in the United States more than in any other country, years of progress in the civil rights of the homosexual minority are at stake. For developing countries, already faced with considerable health problems and severe restrictions on the money available for the health sector, the health impact of AIDS is likely to be especially severe. In developing countries as well, years of economic development are at risk as AIDS siphons off funds for its control and as it decimates the population. Since AIDS is essentially a disease of young, productive adults, many commentators have remarked that from the standpoint of development, AIDS may be especially problematic in the urban areas of Africa, where it may deplete the educated elites.[10]

Interests in adequately confronting the AIDS problem, however, are not limited to the national level. International stakes in AIDS control also exist. What is the interest of the United States, for example, in controlling the pandemic rather than just the U.S. epidemic? What is its stake in international cooperation in AIDS control? Should rich nations that can unilaterally implement AIDS-control interventions concern themselves with the AIDS problem in other countries? Should poor nations that can barely address their own AIDS problem be concerned with AIDS in other nations? In

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what way is the international impact of AIDS the concern of a single nation?

An international interest in AIDS control arises (1) when one nation has an interest in the control of AIDS within another nation, (2) when aspects of the AIDS problem are of mutual concern to two or more nations, (3) when one nation needs others to adequately address the AIDS problem within its own borders, and (4) when health is viewed as a global resource. In general, international cooperation is required to properly address such international interests. It is clear, however, that since international cooperation is usually motivated by the self-interest of the parties involved, no plan to control AIDS through increasing international cooperative effort will remain effective unless it continues to serve the national interests of each nation.[11]

A brief example from the problem of pollution will illustrate the four types of international interests a country may have. First, the United States may be concerned about the problem of pollution in Canada and may have an interest in Canada taking adequate measures to solve it. Second, the United States and Canada may wish to address the problem of pollution as it affects them both, as with the pollution of Lake Michigan by both parties. Third, the United States may need Canadian assistance to deal with the pollution problem within the United States—for example, through the provision of Canadian expertise unavailable in the United States. Fourth, the United States may be concerned about pollution generally because of the threat it poses to the global environment and to life on earth. In all four situations, the U.S. and international interests lie in dealing with the international aspect of the problem. The situation with AIDS is analogous.

Regarding the first situation where international stakes in AIDS control arise, even if AIDS did not affect the United States, for example, the United States might nevertheless want to help control AIDS in central Africa because of humanitarian, economic, and political concerns, as it does with other diseases. The United States may thus have an interest in the control of the pandemic, not merely its own epidemic, out of concern for the political, social, or economic stability of other countries. In a pandemic, however, interests in control both within and without a given country become congruent. That is, Western concern about AIDS in Africa probably arises from

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a confluence of interests that Western nations have in AIDS control within their own borders as well as in other nations. Indeed, most diseases affecting the Third World—even sicknesses such as malaria, for which effective technology for prevention and cure already exist—are not accorded the attention given to AIDS.

The movement of goods and people across national boundaries is typical of the second situation in which international interests in AIDS control arise. Examples include immigration and tourism of HIV-infected individuals, trade in defective condoms and antibody tests, international transport of HIV-infected blood, and interdiction of illegal intravenous drugs. Properly addressing such concerns will require international policy and cooperation. In the effort to control both the export and the transfusion of HIV-contaminated blood, for example, international effort must figure prominently. WHO, in collaboration with the League of Red Cross–Red Crescent Societies, the International Society for Blood Transfusion, and the U.N. Development Program is organizing a global safe-blood program.[12] Part of the impetus for this program has been the possibility of success in controlling this mode of HIV spread, and part has been the expectation that success in this area might further foster international cooperation in AIDS control.

Similarly, concern about international transmission of HIV through sexual contact has led many countries (including Belgium, Bulgaria, China, Costa Rica, West Germany, India, Iraq, South Africa, the United States, and the Soviet Union) to test visiting students, immigrants, and returning nationals for HIV antibodies.[13] In a report on such testing, WHO made prominent note of the fact that "no region of the world is free from HIV infection," as if to stress the futility of border testing in the face of a pandemic disease.[14] Such testing policies have also been appropriately criticized on the grounds that they are expensive, relatively ineffective, and potentially racist. There is an international interest in appropriate and cooperative policy regarding international travel.

A third situation where international interests in the AIDS pandemic arise is where one nation requires the involvement of other nations to confront the AIDS problem optimally. AIDS research is a good example. AIDS research is also illustrative of the obstacles to international cooperation in AIDS control.

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A fourth situation in which international interests in AIDS control arise is when health itself is conceptualized as an international concern.

## OBSTACLES TO COLLABORATIVE AIDS RESEARCH

The conduct of collaborative AIDS research in Africa—generally involving African subjects and American, European, and African scientists—is illustrative of both the need for and the obstacles to international cooperation in AIDS control. Western and African nations have much to gain if an effective means of AIDS prevention or therapy is developed as a result of collaborative research; national interests would clearly be well served by such discoveries.

Africa has been identified as an ideal site for human research trials of AIDS vaccines and drugs for a number of practical and scientific reasons. Many have pointed to the low cost of conducting a trial in Africa because labor is cheap there. There is a scientific need for large study groups, which also militates for the conduct of trials in Africa. The design of studies to test the efficacy of pharmaceutical agents in HIV-infected persons generally involves a trade-off between the number of subjects and the time necessary for the research to show an effect of the pharmaceutical. The need to quickly find efficacious therapy for HIV infection would therefore favor large-scale trials involving many thousands of subjects in many countries. In the trial of an HIV vaccine, research subjects would have to be free of HIV infection and yet at risk of infection; this expectation is easier to meet in Africa than in the developed world.[15] And in the trial of drugs, subjects who are infected with HIV but who do not self-medicate with putative anti-HIV agents ("pharmacologically virgin" subjects) would be required; such subjects are scarce in the United States and Europe but common in Africa. A constellation of epidemiological features that facilitate the assembly of appropriately large study groups thus exists in Africa.

Hence, the United States, for example, needs the assistance of central African nations if it is to make progress in AIDS research. Conversely, African nations—lacking both well-developed research institutions and adequate funds—need the involvement of the developed world if useful AIDS pharmaceuticals are to be developed.

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But the AIDS pandemic presents an enormous challenge to scientists, physicians, public-health officials, politicians, and others concerned about public welfare. Obstacles to international cooperation in the confrontation of the AIDS pandemic may be grouped in five categories: (1) practical issues, (2) diverging national interests, (3) lack of consensus on the nature of the problem, (4) mutual mistrust among nations, and (5) cultural dissonance. Such obstacles are to be expected in all international cooperative efforts, including large-scale vaccination (if an AIDS vaccine becomes available), AIDS prevention, and AIDS research. Identifying the obstacles sometimes makes straightforward solutions obvious. Ways around other obstacles are more elusive.

*Practical Issues*

International cooperation in AIDS research will be hampered by a number of practical concerns. The poor quality of statistics gathered in much of the world where surveillance systems are inadequate will be a problem. In Africa, for example, there is serious underreporting of AIDS cases for a number of political and logistic reasons, though the situation is improving. Even in countries with adequate resources and good surveillance, other limitations in the information that is gathered may arise; in the United States, for example, conducting necessary seroprevalence studies has proven politically problematic. Seroprevalence studies and case surveillance will be necessary for the proper design of AIDS pharmaceutical trials, and, more generally, for proper planning and resource allocation on an international scale. A related practical obstacle to international cooperation is the erroneous or delayed communication between nations of such statistical and other scientific information. Even more ominous, however, is the shortage of trained Third World researchers and clinicians capable of good care and research in Third World settings. Collaborative efforts will depend heavily on the availability of such professionals.

*Diverging National Interests*

Differences in national interests will present obstacles to international cooperation. National interests in AIDS research may diverge according to the particular form the AIDS pandemic takes in particular countries. National research agendas will likely be sensitive to the local expression of the pandemic. For example, the requisite social

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science research on the spread of HIV through drug abuse in Amsterdam will not be the same as that needed to understand the spread through prostitution in Kinshasha. And in some countries, perhaps dictated by low local seroprevalence, the emphasis may be on research to produce preventive rather than curative measures.

National interests may vary with respect to the very need for AIDS research. Health officials of some African nations, for example, have complained that AIDS research has been foisted on them by the West, that they know best how to use their very limited health budget, and that they have more pressing health problems than AIDS. Indeed, the cost of a single HIV antibody test (roughly $1 to $4) approaches the annual per capita health expenditure for many African countries.

### *Lack of Consensus*

Cooperative international effort will ideally be based on consensus about the nature of the problem. In some countries, however, AIDS will largely be viewed as a social problem amenable to a change in morals, in others as a criminal problem meriting police action, in others as an external problem requiring border interdiction, and in still others as a health problem responsive to public-health intervention. Such discrepant views about sexually transmitted diseases are not without precedent.[16] In some countries, a type of national blindness or feeling of immunity may prevail that necessitates persuading people they have a problem to begin with. Differences in perspective about the AIDS problem considerably complicate efforts to reach and sustain a common approach to AIDS control. Nations where drug abuse is illegal, for example, may not be open to the idea of researching the effect of providing clean needles on HIV transmission through intravenous drug use. Essential here is that HIV is transmitted by activities that are viewed differently—generally negatively—in different societies. That HIV is transmitted sexually subverts international cooperation because of profoundly disparate ideas about sex, sexually transmitted diseases, and the susceptibility to infection with sexually transmitted diseases.[17]

### *Mutual Mistrust*

Cooperation will be hampered by mistrust among nations. This problem will likely be exacerbated by virtue of the fact that the two major loci of HIV infection are in the United States, one of the most

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developed regions of the world, and in central Africa, one of the least developed. These two regions have vastly different cultures, economies, politics, and health-care infrastructures.

International mistrust has manifested itself in superfluous arguments about which region is to blame for the origin of HIV.[18] While there are some legitimate reasons for concern regarding the origin of HIV (e.g., the clues it might provide regarding HIV transmission or immunity), such concern is often inappropriately extended to assignment of blame. Precisely for this reason, Africans are very sensitive to the assertion that AIDS originated in Africa. Many Africans feel that they have been victims of "cynical and unhealthy exploitation by the Western press"[19] and have complained that "AIDS has exposed the thinly veiled racism and fascism existing in Europe, because here is a pandemic problem being treated as if it is the scourge of a particular part of the world."[20] Some African officials have asserted that AIDS has arisen in North America[21] and complain that there is little research into this possibility.[22] International misunderstanding is not limited to the developing world, of course, as the controversy over whether French or American researchers first discovered HIV demonstrates.[23]

Differences in economic and political power might also lead to abuse of the poor by the rich and of the weak by the strong, prompting resentment, quite appropriately, in the former. For example, Africans have been concerned that Western investigators, unchecked by foreign or local supervision, might conduct "savage experiments" in Africa. There is a feeling that "Western science often comes to Africa with dirty hands."[24] In view of past experience with occasional disregard for the rights of human subjects of research in Third World countries, this fear is not entirely unjustified.[25] For example, in the case of a recent trial of an AIDS vaccine in Africa, Africans were understandably concerned that they were serving as subjects for research deemed too risky to be conducted in the West. An unidentified source close to the research group conducting the trial informed a *New York Times* reporter that "it was easier to get official permission [to conduct the vaccine trial] here [in Zaire] than in France."[26] Special attention to local concerns about the conduct of research will be necessary.[27] Of course abuse of developing-world research subjects is intolerable.

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African concerns about Western research transcend concerns that subjects might be treated unethically. Many Africans have voiced the more general concern that they do not derive much benefit from their contribution to collaborative research efforts. African physicians have complained that:

> some of the Western press and researchers have used the seropositivity data we supplied, but instead of putting HIV under the microscope, they have put our society, our customs, and even our love life under the lens. Do you find it surprising that some of us resent this? Whatever goes wrong, whether it is famine, war, politics, or anything else, it is always because we Africans are more incompetent, corrupt, blood-thirsty, or immoral than other people. We just get tired of it—we give you information and so often you seem to turn it against us.[28]

To avoid abuse of African subjects in a crude dollars-for-bodies trade in research trials, there must be assurance that all will benefit from the research being conducted. This benefit should extend to study participants (in the form of counseling on risk reduction and, possibly, the provision of other health care) and to the nation in which the study is conducted. The ethical principle of justice requires that those who stand to benefit from research also be those who bear the burden. Since all the world stands to benefit from an effective AIDS vaccine, for example, risks and benefits should be uniformly distributed. In Africa, however, economic constraints may well prevent even modest distribution of a beneficial vaccine, should one be developed. The benefit to Africans of a collaborative vaccine trial is thus only hypothetical unless those developing the vaccine make a financial commitment to provide free or subsidized vaccine to the population in which it is being developed. This commitment should be a contingency of an AIDS vaccine trial conducted in Africa by Western scientists.

### *Cultural Dissonance*

Another obstacle to international cooperation in general and to collaborative AIDS research in particular is cultural dissonance. Profound differences in the cultural conception of illness, sex, medicine, and research have great impact on the facility with which nations can cooperate with one another. An important example of cultural dissonance is provided by differing cultural conceptions of biomedical research ethics.[29]

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A system of ethics is a set of rules governing the proper, moral, and desirable conduct of an individual or group; it is fashioned by a particular group of individuals within a particular cultural tradition. The ethical expectations regarding research with human subjects therefore vary cross-culturally. Biomedical ethics may thus provide an arena for cultural conflict. Indeed, conflict in research ethics might be expected to exacerbate other conflicts that sometimes arise when the Western medical tradition is transposed into a non-Western cultural setting.[30] The AIDS pandemic has called into question the basing of research ethics on Western ideals because, here, the same disease occurs throughout the world in disparate cultural settings, everywhere drawing research interest, and everywhere raising ethical questions.

## MEDICINE AND HEALTH AS RESOURCES HELD IN COMMON

International interests in AIDS control also arise if medicine and health are viewed in international perspective. As we have seen, some of the necessary biomedical research on AIDS will involve the participation of many countries. The need for and conduct of such research is illustrative of the increasingly international character of medicine and health. More generally, the control of the AIDS pandemic should not be based solely on Western ideas and technology. Western ideas and technologies are insufficient on two levels.

Western biomedicine is insufficient on the technical level. It is extremely expensive, especially for the developing world; the widespread distribution of the anti-AIDS drug AZT, for example, which costs about $7,000 per person per year of therapy, is inconceivable in countries like Zaire. Furthermore, the demands of biomedicine for equipment and supplies are often so great as to make it impracticable in many settings; abridged versions such as "primary health care" are therefore usually offered. Biomedicine is especially weak in dealing with chronic disease, where the emphasis is on care rather than cure; it often neglects the essential importance of suffering in illness;[31] this deficiency will be troublesome since it is becoming increasingly likely that AIDS will be more of a chronic than an acute condition. Also, biomedicine generally stresses delivery of care to an individual; such individual-based medicine may be inappropriate in many settings,

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especially in Africa, where illness is sometimes viewed as a social as well as a personal phenomenon. Finally, biomedicine may be too culturally distant from patients in much of the world. These limitations in biomedicine mean that it alone is not sufficient for the proper medical care throughout the world of people at risk of infection or already infected with HIV.

Nevertheless, that the biomedical control of AIDS is problematic does not mean that AIDS will be more easily confronted by other medical systems. Despite its limitations, biomedicine clearly offers promise in the global control of AIDS. One goal in global AIDS control should be to make Western biomedicine transferable to disparate socioeconomic settings.

Western views of health, medicine, and disease are insufficient on the conceptual level because they tend to be reductionistic. Disease is seen as a physiological derangement within the body that undermines an individual's health. Generally, to understand disease and its effect on health, a form of analysis is applied that moves sequentially through progressively finer levels, from symptoms to organ systems to cellular processes to biochemical abnormalities to genetic constitutions. Doctors intervene in the course of the disease in the affected individual in an attempt to arrest or reverse it. Health is therefore seen as the state of individual well-being that is generally improved by medicine and worsened by disease.[32]

Health, however, is not simply the antithesis of disease, an antithesis mediated through the action of medicine at the level of the individual. Health may be conceptualized at a level greater than that of the individual.

A reductionistic approach is not sufficient for effective AIDS control. Indeed, a type of thinking that stands in contrast to the traditional scientific approach in the understanding of AIDS will also be required. The only way to control AIDS will be to examine the interaction between the affected or susceptible individuals and their environments and to determine the causes of disease and health that are extrinsic to the individual. In addition to moving analysis inward, within the bodies of AIDS victims, we must move outward toward an understanding of the relationship between the patient and his sexual partner, his family, his doctor, his community, and beyond. We must examine how these concentric circles interact with each other. We must understand the worldwide ecology of the pandemic.

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When confronting the AIDS pandemic, a national AIDS epidemic, or an AIDS patient, one must keep in mind that each exists because of the others, each acquires some of its properties from its relation to the others, and aspects of all three evolve because of their interaction.[33] The AIDS pandemic is not simply the sum of the epidemics faced in all the nations of the world nor simply the sum of the AIDS problems faced by all the inhabitants of the globe. The whole is greater than the sum of the parts.

Just because the global AIDS problem can be approached at subordinate levels does not mean that this is the true nature of the problem. As an example, consider the need to approach an infected person's sexual partners. In this situation, addressing only the concerns of the infected individual is clearly an inadequate response to the problem. On this small scale, ecological thinking is employed: ideally, the partner or partners are approached to be tested, treated, or counseled. The degree to which others must be included in the approach to the AIDS problem should be extended even further. As we have seen, certain aspects of the AIDS pandemic can be addressed only through international effort.

Such an approach to the AIDS pandemic will in turn require renewed sensitivity to the international character of medicine and health. With respect to medicine, the nature of the AIDS problem has come to be understood by a concerted international effort involving the participation of physicians, patients, and research subjects from the United States, Europe, and Africa. The AIDS pandemic will reinforce the idea that medical knowledge is nonproprietary. Medical knowledge is created through the observation of and experimentation on generations of sick patients. Medical professionals hold the knowledge acquired through such activities in trust for the good of the sick.[34] Because of the special and intimate way medical knowledge is acquired—from the illness of human beings over the course of time—it should not belong to any particular person or group. Advances in AIDS research should therefore not be seen as appropriately benefiting only certain societies. No rational distinction can be made between the sick in one society and the sick in another with respect to who deserves, in a moral sense, the benefits of medical knowledge. The AIDS pandemic forces us to see that confining the ethical imperative to treat the sick within national boundaries weakens rather than strengthens the altruistic basis of medicine.[35] Given

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the increasingly international character of modern Western biomedicine, confining the ethical obligation to treat within the West is even more inappropriate.

An international view of health is also suggested by the AIDS pandemic. From the position that health is the responsibility of the individual, the notion of public health has historically arisen in recognition of the fact that certain aspects of health preservation are outside the control of the individual. Concerns that are largely beyond the control of individuals, such as sanitation or communicable disease control, have come to be recognized as requiring a concerted societal response, and the national government has emerged as an important protector of the health of its citizens. This progression may be extended to the international level. The public that public health serves must be more broadly construed in order to reflect the international stakes in AIDS control. Certain aspects of health preservation may now be seen as requiring international attention.

The AIDS pandemic suggests a further profound change in the way health is perceived. Health is usually viewed on the level of the individual, as the absence of disease in a body. Occasionally, health is viewed on the level of a nation, in the measurement of national health statistics or indicators. Even in the latter case, however, the health of a nation is seen as the aggregate sum of the health of its constituent individuals, and health-status indicators merely represent the sum of events, such as death or injury, seen in individuals.

The AIDS pandemic suggests a change in this view: health may be conceptualized as a resource held in common, like the oceans, a resource that may be threatened worldwide and that requires collective action to protect.

Viewing health as the possession of the individual is a Western notion, stemming in part from the congruence with which we view the phenomena of the body, the individual, and the person. But in some non-Western cultures, such phenomena are incongruent.[36] Some cultures have more relational concepts of personhood, concepts that emphasize the embeddedness of an individual within society, and draw much looser boundaries around the person. The Kongo of Lower Zaire, for example, have conceptions of illness that "consistently [draw] the effective boundary of a person differently, more expansively, than classical Western medicine, philosophy, and reli-

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gion. The outcome is usually disconcerting or unreal to Western medical observers."[37] The very definition of the body in Kongo culture is achieved by means of constant reference to social relations. As a result, disease in one body is often seen as reflective of disturbance in the group and is considered to be the problem of the community. In the West, by contrast, persons are generally defined as autonomous individuals; problems with the body are therefore seen as the concern of the person.[38]

Health, in other words, may be conceptualized as a possession of a group of people, a resource not belonging solely to individuals. A key aspect of this type of resource is that concerted effort is required to preserve it, lest the resource be depleted.[39] The narrow, nationalistic policy that AIDS may be controlled within a single country neglects the international character of what the AIDS pandemic threatens.

A step toward viewing health as a common resource was made in 1978 at a conference sponsored by WHO and UNICEF in the Soviet Union at Alma Ata. At this conference, a historic consensus on the worldwide promotion of community-based, primary health care was reached. The conference participants articulated an international goal that "all people of the world by the year 2000 [attain] a level of health that will permit them to lead a socially and economically productive life."[40] More remarkably, however, the Alma Ata declaration stated that:

> All countries should cooperate in a spirit of partnership and service to ensure primary health care for all people, since the attainment of health by people in any one country directly concerns and benefits every other country.

The declaration thus essentially articulated the notion of health interdependence among nations.[41] The AIDS pandemic provides a pragmatic foundation for this notion. The reason that nations are interdependent in the area of health transcends the empirical observations that diseases spread or that physicians move. The reason that nations are interdependent in health is that the health of humanity may be viewed as a common resource.

## THE ROLE OF INTERNATIONAL ORGANIZATIONS

As we have seen, some of the stakes raised by the AIDS pandemic are international in character and require international cooperative effort

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to address. For a worldwide program in AIDS control to be effective, however, there must be some agency for coordinating and monitoring the work. International efforts are difficult to manage given the realities of national sovereignty and the acknowledged limitations of international bureaucratic organizations. Nevertheless, international organizations can contribute to an international effort by supplying a continuity of professional staff that is experienced with AIDS and able to move from country to country, by coordinating the distribution and monitoring the quality of pharmaceuticals used worldwide, by redirecting discretionary funds to areas where they are needed acutely, by promulgating international guidelines and distributing information, and by coordinating international strategy once it is formulated.[42] In general, international organizations such as WHO can implement international policy.

International policy is more appropriate and international organizations are more suited to addressing certain aspects of the AIDS pandemic than others. There are some important advantages to responding to AIDS at the national level. When international organizations are used to coordinate a series of national responses, or when they are used to deliver care at a local level, they often neglect local sociocultural issues and are therefore ineffective.[43] A national response is likely to be more sensitive to local factors than an international response. A response based on the concerns of a single nation may allow local priorities to be set in a more appropriate fashion. And a national response is more flexible and less cumbersome than an international effort in which policies are set at a central level. Recognizing the importance of the foregoing concerns, a prominent component of the international efforts by the WHO Special Program on AIDS has been to foster national initiatives to control AIDS that are in keeping with international goals.[44] Indeed, an international effort does not preclude national efforts to control AIDS; ideally, it should complement them.

An international approach is less useful in AIDS control when the aspect of the problem being addressed is not technical. The more a health problem is influenced by social and cultural factors, the less there will be for an international organization to do. Sexuality, for example, is so deeply surrounded by local cultural traditions that an international approach directed at changing sexual behavior is inappropriate in most situations. Both the understanding and the control

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of HIV transmission through prostitution are likely to be very different in Paris, Rio de Janeiro, Port-au-Prince, New York, and Kinshasha.

Paradoxically, therefore, in some aspects of AIDS control, a global strategy must recognize local diversity. Educational policy, for example, being profoundly influenced by local sociocultural factors, may best be left to the national level. Given the way health care is financed, the provision of medical services is also probably necessarily left to the national level. AIDS research and the collection of seroprevalence data, however, are more appropriate concerns of international organizations. This is not to say that the scientific and technical concerns in AIDS control are not influenced by social factors. Rather, such concerns may be more amenable to international consensus and cooperation.

International organizations are relatively good at addressing technical and scientific aspects of international health problems. When the problem is configured as a technical one, WHO is apt to be especially effective; for example, in the case of the global smallpox eradication program, where a similar protocol could be used everywhere, WHO was extremely successful.[45] International organizations can thus do a great deal to address practical and technical obstacles to international cooperative efforts. WHO has appropriately played a role in addressing such obstacles, for example, through the development of a global data-reporting network and the coordination of research efforts. But there are some further steps that need attention in the confrontation of the AIDS pandemic and that deserve the attention of WHO.

Cooperative intervention will be needed to take initiative where there is little private-sector incentive to intervene (e.g., in the development of a low-cost HIV test that would be usable in Third World countries).[46] Cooperative effort is required to improve the basic health-care infrastructure of developing countries; even if an AIDS vaccine were available and both developing and developed countries desired widespread vaccination, infrastructural constraints would make worldwide vaccination very difficult. Cooperative effort is needed to strengthen Third World capabilities in medical care and research; limitations in the quantity, training, and facilities of researchers in the developing world, in both basic and social sciences, are a serious problem.[47]

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Assuming effective technological interventions in the prevention and therapy of AIDS are eventually discovered, and assuming AIDS persists at a time when such technology exists—as seems likely given the experience with other widespread diseases—the global AIDS problem will then no longer be primarily a technological one. That is, in the future, should an AIDS vaccine, for example, become available and should it not come to be universally applied because of political, cultural, or financial obstacles, the challenge will be to overcome these nonscientific obstacles. Unfortunately, international organizations will likely be of limited efficacy in these areas.

## AIDS AS A PERMANENT INTERNATIONAL PROBLEM

The AIDS pandemic illuminates some critical polarities in which international health problems may be configured. There is a distinction between pandemic and epidemic disease. There is a distinction between international and national interests in AIDS control, between the global and the local effects of the disease, and between systemic and reductionistic perceptions of the AIDS problem. These polar configurations of the AIDS problem are not mutually exclusive. Rather, they are complementary ways of conceptualizing and addressing the important issues in global AIDS control.

A pandemic disease cannot be addressed in the same manner as an epidemic disease. While the AIDS pandemic clearly demands a series of national responses, an international response is also necessary. AIDS creates a special set of international issues that would not have arisen had the disease affected only one nation or region. AIDS demonstrates the increasing interdependence between nations in the area of health.

In all probability, AIDS will never be eradicated. It is likely to become a permanent part of the international agenda, much like arms control and pollution. The more the international character of AIDS is recognized, the easier it will be to establish proper institutional and conceptual bases for addressing the international interests in AIDS control.

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ENDNOTES

I am grateful to Professors Allan M. Brandt, Richard A. Cash, Alexander N. Christakis, Stephen R. Graubard, and Arthur M. Kleinman for their helpful comments on earlier versions of this paper.

[1]World Health Organization, *The Global AIDS Situation, Update March 1988, 54* (Geneva: World Health Organization, 1988).

[2]The Panos Institute, *AIDS and the Third World, Update* (Washington, D.C.: The Panos Institute, 1988).

[3]"Human Immunodeficiency Virus Infection in the United States," *Morbidity and Mortality Weekly Report* 36 (49) (1987):801–4; "Quarterly Report to the Domestic Policy Council on the Prevalence and Rate of Spread of HIV and AIDS—United States," *Morbidity and Mortality Weekly Report* 37 (36) (1988): 551–54. The variation in these estimates depends on the group sampled, e.g., first-time blood donors, military recruits, hospitalized patients.

[4]T. C. Quinn et al., "AIDS in Africa: An Epidemiological Paradigm," *Science* 234 (21 November 1986):955–63. The variation in these estimates depends on the country surveyed and the group sampled.

[5]R. M. Anderson, R. M. May, and A. R. McLean, "Possible Demographic Consequences of AIDS in Developing Countries," *Nature* 332 (17 March 1988): 228–33.

[6]Professor W. Curran, Harvard School of Public Health, personal communication, October 1988; see also: World Health Organization, *Tabular Information on Legal Instruments Dealing With AIDS and HIV Infection*, document WHO/SPA/HLE/87.1 (Geneva: World Health Organization, 1987).

[7]Regarding the 1918 influenza pandemic, see W. I. B. Beveridge, *Influenza: The Last Great Plague* (New York: Prodist, 1977).

[8]Other medical systems, such as Ayurveda, will also likely be used, but not in a systematic fashion throughout the world.

[9]A. A. Scitovsky and D. P. Rice, "Estimates of the Direct and Indirect Costs of Acquired Immunodeficiency Syndrome in the United States, 1985, 1986, and 1991," *Public Health Reports* 102 (1) (1987):5–17.

[10]M. F. Goldsmith, "AIDS around the World: Analyzing Complex Problems," *Journal of the American Medical Association* 259 (13) (1988):1917–19.

[11]For a discussion in the case of arms control, see R. R. Bowie, "Basic Requirments of Arms Control," *Dædalus* 89 (4) (1960):708–22.

[12]M. E. Samuels, J. Mann, and C. E. Koop, "Containing the Spread of HIV Infection: A World Health Priority," *Public Health Reports* 103 (3) (1988): 221–23.

[13]Panos Institute.

[14]World Health Organization, *Report of the Consultation on International Travel and HIV Infection*, document WHO/SPA/GLO/87.1 (Geneva: World Health Organization, April 1987).

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[15]N. A. Christakis, "The Ethical Design of an AIDS Vaccine Trial in Africa," *Hastings Center Report* 18 (3) (1988): 31–37.

[16]A. M. Brandt, *No Magic Bullet: A Social History of Venereal Disease in the United States since 1880* (New York: Oxford University Press, 1987).

[17]For an example of various sexual mores, see R. Parker, "Acquired Immunodeficiency Syndrome in Urban Brazil," *Medical Anthropology Quarterly* 2 (1) (1988):155–75.

[18]R. Sabatier, *Blaming Others: Prejudice, Race, and Worldwide AIDS* (Philadelphia: New Society Publishers, 1988).

[19]J. Brooke, "AIDS Danger: Africa Seems of Two Minds," *The New York Times*, 4 January 1987; see also, J. Brooke, "In Cradle of AIDS Theory, a Defensive Africa Sees Disguise for Racism," *New York Times*, 19 November 1987.

[20]T. Agbabiaka, "Racist Bigotry on AIDS," *African Concord*, 4 June 1987.

[21]See generally R. Sabatier.

[22]But see H. P. Katner and G. A. Pankey, "Evidence for a Euro-American Origin of Human Immunodeficiency Virus," *Journal of the National Medical Association* 79 (10)(1987):1068–72.

[23]L. C. Chen, "The AIDS Pandemic: An Internationalist Approach to Disease Control," *Dædalus* 116 (2) (1987):181–95.

[24]A. J. Fortin, "The Politics of AIDS in Kenya," *Third World Quarterly* 9 (3)(1987): 906–19.

[25]See, for example, C. McCord, "International Research Laboratory in Bangladesh," *The Lancet* (i) (1978):768; D. Warwick, "Contraceptives in the Third World," *Hastings Center Report* 5 (4) (1975):9–12.

[26]J. Brooke, "Zaire, Ending Secrecy, Attacks AIDS Openly," *New York Times*, 8 February 1987.

[27]N. A. Christakis, "Ethical Design of an AIDS Vaccine Trial."

[28]Quoted in R. Sabatier, 89–90.

[29]N. A. Christakis, "Which Ethics for Transcultural Biomedical Research?" (forthcoming).

[30]P. U. Unschuld, "Medico-Cultural Conflicts in Asian Settings: An Explanatory Theory," *Social Science and Medicine* 9 (6B)(1975):303–12.

[31]A. Kleinman, *The Illness Narratives: Suffering, Healing, and the Human Condition* (New York: Basic Books, 1988).

[32]This is, of course, too simple a formulation; see I. Illich, *Medical Nemesis: The Expropriation of Health* (New York: Pantheon Books, 1976).

[33]For further consideration of this idea in a biological context, see R. Levins and R. Lewontin, *The Dialectical Biologist* (Cambridge: Harvard University Press, 1985).

[34]E. D. Pellegrino, "Altruism, Self-interest, and Medical Ethics," *Journal of the American Medical Association* 258 (14) (1987):1939–40.

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[35]L. C. Chen and R. A. Cash, "A Decade After Alma Ata: Can Primary Health Care Lead to Health for All?" *New England Journal of Medicine* 319 (14) (1988): 946–47.

[36]See W. DeCraemer, "A Cross-Cultural Perspective on Personhood," *Millbank Memorial Fund Quarterly* 61 (1) (1983):19–34; and also, C. Geertz, "Person, Time, and Conduct in Bali," in C. Geertz, *The Interpretation of Cultures* (New York: Basic Books, 1973).

[37]J. M. Janzen, *The Quest for Therapy in Lower Zaire* (Berkeley: The University of California Press, 1978), 189.

[38]However, some Western health-care systems do make illness and well-being the responsibility of the community. See R. G. Evans, " 'We'll Take Care of It for You,' Health Care in the Canadian Community," *Dædalus* 117 (4) (1988): 155–90.

[39]G. Hardin, "The Tragedy of the Commons," *Science* 162 (13 December 1968): 1243.

[40]World Health Organization, "Alma Ata 1978, Primary Health Care" (Geneva: World Health Organization, 1978).

[41]Some have argued that the AIDS pandemic highlights the importance of global health interdependence; see L. C. Chen, "The AIDS Pandemic: An Internationalist Approach to Disease Control."

[42]For a discussion of the role of WHO, which is analogous to that described here, in the global effort to control smallpox, see F. Fenner et al., "Lessons and Benefits," in *Smallpox and Its Eradication* (Geneva: World Health Organization, 1988).

[43]J. Justice, *Policies, Plans, and Peoples: Culture and Health Development in Nepal* (Berkeley: University of California Press, 1986).

[44]World Health Organization, *Special Program on AIDS, Progress Report #2*, document WHO/SPA/GEN/87.4 (November 1987).

[45]See F. Fenner et al..

[46]Public–private sector arrangements in the development of AIDS technologies require careful consideration; see N. A. Christakis and M. J. Panner, "Appropriate Collaboration between Industry and Government in the Development of an AIDS Vaccine," *Law, Medicine & Health Care* 17 (2) (1989) (in press).

[47]For an example of complaints by African officials, see J. Perlez, "Scientists From Western Countries Pressing for AIDS Studies in Africa," *New York Times*, 20 September 1988. Faced with the increasing pressure of Western scientists to permit HIV research in their countries, African physicians have also repeatedly pointed out that they are interested in genuine cooperation and not a subservient status.

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*Paul Farmer and Arthur Kleinman, M.D.*

# AIDS as Human Suffering

*This plague has attracted the inevitable swarm of AIDS researchers, officials, businessmen, and journalists, and they are the ones who have monopolized the media. We people with AIDS, who devote each waking moment to our own survival, have been unable to prevent those loquacious experts from stealing our thunder and robbing us of the only thing we have left: our illness.*

—Emmanuel Dreuilhe[1]

*The age-old, seemingly inexorable, process whereby diseases acquire meanings (by coming to stand for people's deepest fears) and inflict stigma is always worth challenging, and it does seem to have a more limited credibility in the modern world; the process itself is being questioned now. With this illness, one that elicits so much guilt and shame, the efforts to detach it from loaded meanings and misleading metaphors seem particularly liberating, even consoling.*

—Susan Sontag[2]

THAT THE DOMINANT DISCOURSE ON AIDS at the close of the twentieth century is in the rational-technical language of disease control was certainly to be expected and even necessary. We anticipate hearing a great deal about the molecular biology

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of the virus, the clinical epidemiology of the disease's course, and the pharmacological engineering of effective treatments. Other of contemporary society's key idioms for describing life's troubles also express our reaction to AIDS: the political-economic talk of public-policy experts, the social-welfare jargon of the politicians and bureaucrats, and the latest psychological terminology of mental-health professionals. Beneath the action-oriented verbs and reassuringly new nouns of these experts' distancing terminology, the more earthy, emotional rumblings of the frightened, the accusatory, the hate-filled, and the confused members of the public are reminders that our response to AIDS emerges from deep and dividing forces in our experience and our culture.

## AIDS AND HUMAN MEANINGS

Listen to the words of persons with AIDS and others affected by our society's reaction to the new syndrome:

- "I'm 42 years old. I have AIDS. I have no job. I do get $300 a month from social security and the state. I will soon receive $64 a month in food stamps. I am severely depressed. I cannot live on $300 a month. After $120 a month for rent and $120 a month for therapy, I am left with $60 for food and vitamins and other doctors and maybe acupuncture treatments and my share of utilities and oil and wood for heat. I'm sure I've forgotten several expenses like a movie once in a while and a newspaper and a book."[3]
- "I don't know what my life expectancy is going to be, but I certainly know the quality is improved. I know that not accepting the shame or the guilt or the stigma that people would throw on me has certainly extended my life expectancy. I know that being very up-front with my friends, and my family and coworkers, reduced a tremendous amount of stress, and I would encourage people to be very open with friends, and if they can't handle it, then that's their problem and they're going to have to cope with it."
- "Here we are at an international AIDS conference. Yesterday a woman came up to me and said, 'May I have two minutes of your time?' She said, 'I'm asking doctors how they feel about treating AIDS patients.' And I said, 'Well, actually I'm not a doctor. I'm an

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AIDS patient,' and as she was shaking hands, her hand whipped away, she took two steps backward, and the look of horror on her face was absolutely diabolical."

- "My wife and I have lived here [in the United States] for fifteen years, and we speak English well, and I do O.K. driving. But the hardest time I've had in all my life, harder than Haiti, was when people would refuse to get in my cab when they discovered I was from Haiti [and therefore in their minds, a potential carrier of HIV]. It got so we would pretend to be from somewhere else, which is the worst thing you can do, I think."

All illnesses are metaphors. They absorb and radiate the personalities and social conditions of those who experience symptoms and treatments. Only a few illnesses, however, carry such cultural salience that they become icons of the times. Like tuberculosis in *fin de siècle* Europe, like cancer in the first half of the American century, and like leprosy from Leviticus to the present, AIDS speaks of the menace and losses of the times. It marks the sick person, encasing the afflicted in an exoskeleton of peculiarly powerful meanings: the terror of a lingering and untimely death, the panic of contagion, the guilt of "self-earned" illness. There is the ironic meaning of a new incurable infection at a time when other infectious diseases seem to have been conquered—at least in the technologically advanced West—by a succession of magic bullets. There is the moral meaning of shame and humiliation imposed by the very commercialized culture that has made money from the images of sexuality and drugs: now these same images have been transformed, rationally but still hypocritically (since money is still to be made from the meanings), from desires into risks.

AIDS has offered a new idiom for old gripes. We have used it to blame others: gay men, drug addicts, inner-city ethnics, Haitians, Africans. And we in the United States have, in turn, been accused of spreading and even creating the virus that causes AIDS. The steady progression of persons with AIDS toward the grave, so often via the poor house, has assaulted the comforting idea that risk can be managed. The world turns out to be less controllable and more dangerous, life more fragile than our insurance and welfare models pretend. We have relegated the threat of having to endure irremedi-

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able pain and early death—indeed, the very image of suffering as the paramount reality of daily existence—to past periods in history and to other, poorer societies. Optimism has its place in the scale of American virtues; stoicism and resignation in the face of unremitting hardship—unnecessary character traits in a land of plenty—do not. Suffering had almost vanished from public and private images of our society.

Throughout history and across cultures, life-threatening disorders have provoked questions of control (What do we do?) and bafflement (Why me?). When bubonic plague depopulated fourteenth-century Europe by perhaps as many as half to three-fourths of the population, the black death was construed as a religious problem and a challenge to the moral authority as much or even more than as a public-health problem. Religious transcendence was its metaphor as much as medical crisis.[4] In the late twentieth century, it is not surprising that great advances in scientific knowledge and technological intervention have created our chief responses to questions of control and bafflement. To be sure, the international community of researchers has learned an astonishing amount about the human immunodeficiency virus (HIV) in a very short time. We have the technological expertise to prolong the lives of many people with AIDS and to ameliorate some of the horrendous bodily effects of the virus. Yet bafflement is not driven away by the advance of scientific knowledge, for it points to another aspect of the experience of persons with AIDS that has not received the attention it warrants. It points to a concern that in other periods and in other cultures is at the very center of the societal reaction to dread disease, a concern that resonates with that which is most at stake in the human experience of AIDS even if it receives little attention in academic journals— namely, suffering.

A mortal disease forces questions of dread, of death, and of ultimate meaning to arise. Suffering is a culturally and personally distinctive form of affliction of the human spirit. If pain is distress of the body, suffering is distress of the person and of his or her family and friends. The affliction and death of persons with AIDS create master symbols of suffering; the ethical and emotional responses to AIDS are collective representations of how societies deal with suffering. The stories of sickness of people with AIDS are texts of suffering that we can scan for evidence of how cultures and communities and individuals elaborate the unique textures of personal

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experience out of the impersonal cellular invasion of viral RNA. Furthermore, these illness narratives point toward issues in the AIDS epidemic every bit as salient as control of the spread of infection and treatment of its biological effects.

Viewed from the perspective of suffering, AIDS must rank with smallpox, plague, and leprosy in its capacity to menace and hurt, to burden and spoil human experience, and to elicit questions about the nature of life and its significance. Suffering extends from those afflicted with AIDS to their families and intimates, to the practitioners and institutions who care for them, and to their neighborhoods and the rest of society, who feel threatened by perceived sources of the epidemic and who are thus affected profoundly yet differently by its consequences. Moreover, because this condition is a pandemic affecting populations throughout the world, the experience of AIDS is refracted through greatly varying cultural lenses and social conditions, so that the human consequences of the disease are as distinctive as are these cultures themselves. To get at the culturally distinctive human consequences of such a pandemic, we shall examine the experience of persons with AIDS in the United States and in Haiti.

Our objective is to make the language of suffering more central to the academic and public-health discourse on AIDS. To discuss AIDS as suffering, we must make meanings and experience as salient to the problem of AIDS as are microbes and behavior; we need to make demoralization and threat and hope as legitimate to the public discourse on AIDS as are sexual practices, intravenous drug use, and HIV testing. If we minimize the significance of AIDS as human tragedy, we dehumanize people with AIDS as well as those engaged in the public-health and clinical response to the epidemic. Ultimately, we dehumanize us all.

## ROBERT AND THE DIAGNOSTIC DILEMMA

It was in a large teaching hospital in Boston that we first met Robert, a forty-four-year-old man with AIDS.[5] Robert was not from Boston, but from Chicago, where he had already weathered several of the infections known to strike people with compromised immune function. His most recent battle had been with an organism similar to that which causes tuberculosis but is usually harmless to those with intact immune systems. The infection and the many drugs used to treat it

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had left him debilitated and depressed, and he had come east to visit his sister and regain his strength. On his way home, he was prevented from boarding his plane "for medical reasons." Beset with fever, cough, and severe shortness of breath, Robert went that night to the teaching hospital's emergency ward. Aware of his condition and its prognosis, Robert hoped that the staff there would help him to "get into shape" for the flight back to Chicago.

The physicians in the emergency ward saw their task as straightforward: to identify the cause of Robert's symptoms and, if possible, to treat it. In contemporary medical practice, identifying the cause of respiratory distress in a patient with AIDS entails following what is often called an algorithm. An algorithm, in the culture of biomedicine, is a series of sequential choices, often represented diagrammatically, which helps physicians to make diagnoses and select treatments. In most settings, the algorithms discussed and those actually used are quite different. But in Robert's case, step one, a chest X-ray, suggested the opportunistic lung parasite *Pneumocystis* as a cause for his respiratory distress; step two, examination of his sputum, confirmed it. He was then transferred to a ward in order to begin treatment of his lung infection. Robert was given the drug of choice, but did not improve. His fever, in fact, rose and he seemed more ill than ever. His physicians pondered the algorithm and waited.

After a few days of decline, Robert was found to have trismus: his jaw was locked shut. Because he had previously had oral candidiasis ("thrush"), his trismus and neck pain were thought to suggest the spread of the fungal infection back down the throat and pharynx and into the esophagus—a far more serious process than thrush, which is usually controlled by antifungal agents. Because Robert was unable to open his mouth, the algorithm for documenting esophagitis could not be followed. And so a "GI consult"—Robert has already had several—was called. It was hoped that the gastroenterologists, specialists at passing tubes into both ends of the gastrointestinal tract, would be better able to evaluate the nature of Robert's trismus. Robert had jumped ahead to the point in the algorithm that called for "invasive studies." The trouble is that on the night of his admission he had already declined a similar procedure.

Robert's jaw remained shut. Although he was already emaciated from two years of battle, he refused a feeding tube. Patient refusal is

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never part of an algorithm, and so the team turned to a new kind of logic: Is Robert mentally competent to make such a decision? Is he suffering from AIDS dementia? He was, in the words of one of those treating him, "not with the program." Another member of the team suggested that Robert had "reached the end of the algorithm," but the others disagreed. More diagnostic studies were suggested: in addition to esophagoscopy with biopsy and culture, a CT scan of the neck and head, repeated blood cultures, even a neurological consult. When these studies were mentioned to the patient, his silent stare seemed to fill with anger and despair. Doctors glanced uncomfortably at each other over their pale blue masks. Their suspicions were soon confirmed. In a shaky but decipherable hand, Robert wrote a note: "I just want to be kept clean."

Robert got a good deal more than he asked for, including the feeding tube, the endoscopy, and the CT scan of the neck. He died within hours of the last of these procedures. His physicians felt that they could not have withheld care without having some idea of what was going on.

In the discourse of contemporary biomedicine, Robert's doctors had been confronted with "a diagnostic dilemma." They had not cast the scenario described above as a moral dilemma but had discussed it in rounds as "a compliance problem." This way of talking about the case brings into relief a number of issues in the contemporary United States—not just in the culture of biomedicine but in the larger culture as well. In anthropology, one of the preferred means of examining culturally salient issues is through ethnology: in this case, we shall compare Robert's death in Boston to death from AIDS in a radically different place.

## ANITA AND A DECENT DEATH

The setting is now a small Haitian village. Consisting of fewer than a thousand persons, Do Kay is composed substantially of peasant farmers who were displaced some thirty years ago by Haiti's largest dam. Before 1956, the village of Kay was situated in a broad and fertile valley near the banks of a large river. When the valley was flooded to build a hydroelectric dam, the majority of villagers were forced up into the hills on either side of the new reservoir. Kay became divided into "Do" (those who settled on the stony backs of

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the hills) and "Ba" (those who remained down near the new waterline). By all the standard measures, Kay is now very poor; its older inhabitants often blame their poverty on the massive buttress dam a few miles away and note bitterly that it has brought them neither electricity nor water.

When the first author of this paper began working in Kay, in May of 1983, the word *sida*, meaning AIDS, was just beginning to make its way into the rural Haitian lexicon. Interest in the illness was almost universal less than three years later. It was about then that Anita's intractable cough was attributed to tuberculosis. We first met her as a patient in a study on the determinants of the course and outcome of that disease in rural Haiti.

Questions about her illness often evoked long responses. She resisted our attempts to focus discussions. "Let me tell you the story from the beginning," she once said; "otherwise you will understand nothing at all."

Anita was a native of Kay in the true sense of the word. Her mother was born down in the valley and inherited with her brothers a choice bit of farmland that promised to keep them all prosperous and well fed. Anita's father was from a neighboring settlement. The dam altered their fortunes overnight, it seemed, and it was a dispirited woman who later gave birth, up on Do Kay, to Anita. As a little girl, Anita recalls, she was frightened by the arguments her parents would have in the dry seasons. When her mother began coughing, the family sold their livestock in order to buy "a consultation" with a distinguished doctor in the capital. Tuberculosis, he told them, and the family felt there was little they could do other than take irregular trips to Port-au-Prince and make equally irregular attempts to placate the gods who might protect the woman. Anita dropped out of school to help take care of her mother, who died shortly after the girl's thirteenth birthday.

It was very nearly the *coup de grâce* for her father, who became depressed and abusive. Anita, the oldest of five children, bore the brunt of his spleen. "One day, I'd just had it with his yelling. I took what money I could find, about $2, and left for the city. I didn't know where to go." Anita had the good fortune to find a family in need of a maid. The two women in the household had jobs in a U.S.-owned assembly plant; the husband of one ran a snack concession out of the house. Anita received a meal a day, a bit of dry floor to sleep on, and

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$10 per month for what sounded like incessant labor. She was not unhappy with the arrangement, which lasted until both women were fired for participating in "political meetings." Unable to make ends meet, the family made plans to emigrate to the bigger job market in the United States.

Anita wandered about for two days until she happened upon a kinswoman selling gum and candies near a downtown theater. She was, Anita related, "a sort of aunt." Anita could come and stay with her, the aunt said, as long as she could help pay the rent. And so Anita moved into Cité Simone, the sprawling slum on the northern fringes of the capital.

It was through the offices of her aunt that she met Vincent, one of the few men in the neighborhood with anything resembling a job: "He unloaded the whites' luggage at the airport." Vincent made a living from tourists' tips. In 1982, the year before Haiti became associated, in the North American press, with AIDS, the city of Port-au-Prince counted tourism as its chief industry. In the setting of an unemployment rate of greater than 60 percent, Vincent could command considerable respect. He turned his attention to Anita. "What could I do, really? He had a good job. My aunt thought I should go with him." Anita was not yet fifteen when she entered her first and only sexual union. Her lover set her up in a shack in the same neighborhood. Anita cooked and washed and waited for him.

When Vincent fell ill, Anita again became a nurse. It began insidiously, she recalls: night sweats, loss of appetite, swollen lymph nodes. Then came months of unpredictable and debilitating diarrhea. "We tried everything—doctors, charlatans, herbal remedies, injections, prayers." After a year of decline, she took Vincent to his hometown in the south of Haiti. There it was revealed that Vincent's illness was the result of malign magic: "It was one of the men at the airport who did this to him. The man wanted Vincent's job. He sent an AIDS death to him."

The voodoo priest who heard their story and deciphered the signs was straightforward. He told Anita and Vincent's family that the sick man's chances were slim, even with the appropriate interventions. There were, however, steps to be taken. He outlined them, and the family followed them, but still Vincent succumbed. "When he died, I felt spent. I coudn't get out of bed. I thought that his family would try to help me to get better, but they didn't. I knew I needed to go home."

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She made it as far as Croix-des-Bouquets, a large market town at least two hours from Kay. There she collapsed, feverish and coughing, and was taken in by a woman who lived near the market. She stayed for a month, unable to walk, until her father came to take her back home. Five years had elapsed since she'd last seen him. Anita's father was by then a friendly but broken-down man with a leaking roof over his one-room, dirt-floor hut. It was no place for a sick woman, the villagers said, and Anita's godmother, honoring twenty-year-old vows, made room in her overcrowded but dry house.

Anita was diagnosed as having tuberculosis, and she responded to antituberculosis therapy. But six months after the initiation of treatment, she declined rapidly. Convinced that she was indeed taking her medications, we were concerned about AIDS, especially on hearing of the death of her lover. Anita's father was poised to sell his last bit of land in order to "buy more nourishing food for the child." It was imperative that the underlying cause of Anita's poor response to treatment be found. A laboratory test confirmed our suspicions.

Anita's father and godmother alone were apprised of the test results. When asked what she knew about AIDS, the godmother responded, "AIDS is an infectious disease that has no cure. You can get it from the blood of an infected person." For this reason, she said, she had nothing to fear in caring for Anita. Further, she was adamant that Anita not be told of her diagnosis—"That will only make her suffer more"—and skeptical about the value of the AIDS clinic in Port-au-Prince. "Why should we take her there?" asked Anita's godmother wearily. "She will not recover from this disease. She will have to endure the heat and humiliation of the clinic. She will not find a cool place to lie down. What she might find is a pill or an injection to make her feel more comfortable for a short time. I can do better than that."

And that is what Anita's godmother proceeded to do. She attempted to sit Anita up every day and encouraged her to drink a broth promised to "make her better." The godmother kept her as clean as possible, consecrating the family's two sheets to her goddaughter. She gave Anita her pillow and stuffed a sack with rags for herself. The only thing she requested from us at the clinic was "a beautiful soft wool blanket that will not irritate the child's skin."

In one of several thoughtful interviews accorded us, Anita's godmother insisted that "for some people, a decent death is as

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important as a decent life. . . . The child has had a hard life; her life has always been difficult. It's important that she be washed of bitterness and regret before she dies." Anita was herself very philosophic in her last months. She seemed to know of her diagnosis. Although she never mentioned the word *sida*, she did speak of the resignation appropriate to "diseases from which you cannot escape." She stated, too, that she was "dying from the sickness that took Vincent," although she denied that she had been the victim of witchcraft—"I simply caught it from him."

Anita did not ask to be taken to a hospital, nor did her slow decline occasion any request for further diagnostic tests. What she most wanted was a radio—"for the news and the music"—and a lambswool blanket. She especially enjoyed the opportunity to "recount my life," and we were able to listen to her narrative until hours before her death.

## AIDS IN CULTURAL CONTEXT

We asserted at the outset that the way in which a person, a family, or a community responds to AIDS may reveal a great deal about core cultural values. Robert's story underlines our reliance on technological answers to moral and medical questions. "Americans love machines more than life itself," asserts author Philip Slater in a compelling analysis of middle-class North American culture. "Any challenge to the technological-over-social priority threatens to expose the fact that Americans have lost their manhood and their capacity to control their environment."[6] One of the less noticed but perhaps one of the farthest-reaching consequences of the AIDS epidemic has been the weakening of North America's traditional confidence in the ability of its experts to solve every kind of problem. In the words of one person with the disorder, "The terror of AIDS lies in the collapse of our faith in technology."[7]

This core cultural value is nowhere more evident than in contemporary tertiary medicine, which remains the locus of care for the vast majority of AIDS patients. Despite the uniformity of treatment outcome, despite the lack of proven efficacy of many diagnostic and therapeutic procedures, despite their high costs, it has been difficult for practitioners to limit their recourse to these interventions. "When

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you're at Disney World," remarked one of Robert's physicians ironically, "you take all the rides."

Robert's illness raises issues that turn about questions of autonomy and accountability. The concept of autonomous individuals who are solely responsible for their fate, including their illness, is a powerful cultural premise in North American society. On the positive side, this concept supports concern for individual rights and respect for individual differences and achievement. A more ominous aspect of this core cultural orientation is that it often justifies blaming the victims. The poor are viewed as unable to pull themselves up by their own bootstraps. Individual effects of powerful social forces beyond personal control are discounted. Alcoholics, those dependent on drugs, smokers who have developed emphysema, obese victims of heart attacks, chronic pain patients, even some sufferers from cancer—those who bottle up anger or who eat high-fat, low-fiber diets—all are seen as personally accountable for their disorders. Illness is said to be the outcome of their free choice of high-risk behavior.

This has been especially true in the AIDS epidemic, which has reified an invidious distinction between "innocent victims"—infants and hemophiliacs—and, by implication, "the guilty"—persons with AIDS who are homosexuals or intravenous drug users. Robert's lonely and medicalized death is what so many North Americans fear: "He was terrified. He knew what AIDS meant. He knew what happens. Your friends desert you, your lover kicks you out into the street. You get fired, you get evicted from your apartment. You're a leper. You die alone."[8] The conflation of correlation and responsibility has the effect of making sufferers feel guilt and shame. The validity of their experience is contested. Suffering, once delegitimated, is complicated and even distorted; our response to the sufferer, blocked.

In contrast, in Haiti and in many African and Asian societies, where individual rights are often underemphasized and also frequently unprotected, and where the idea of personal accountability is less powerful than is the idea of the primacy of social relationships, blaming the victim is also a less frequent response to AIDS. It is not that patterns of blame have not been discerned in rural Haiti: wherever AIDS strikes, it seems, accusation is never far behind. But in at least one Haitian village, what we have observed is not at all the

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American-style hysteria that initially, at least, spoiled our response to the disease. The reluctance of health-care professionals to care for patients, the angry parents who refuse to send their children to schools with children who have AIDS—these are not features of the rural Haitian response to AIDS. Noticeably absent is the revulsion with which AIDS patients have been faced in the United States, in both clinical settings and in their communities. This striking difference cannot be ascribed to Haitian ignorance of modes of transmission. On the contrary, the Haitians we have interviewed have ideas of etiology and epidemiology that reflect the incursion of the "North American ideology" of AIDS—that the disease is caused by a virus and is somehow related to homosexuality and contaminated blood. These are subsumed, however, in properly Haitian beliefs about illness causation. Long before the advent of AIDS to Do Kay, we might have asked the following question: some fatal diseases are known to be caused by "microbes" but may also be "sent" by someone; is *sida* such a disease?

It is, certain Haitians have told us, so accusations of witchcraft should not have come as a surprise. Although some would cast their analyses in terms of the familiar antinomy of voodoo and Christianity, our informants—who are from Do Kay or surrounding villages—speak in less Manichaean terms. A series of oppositions, rather than one, seems to guide much of our conversation about AIDS and other disorders: an illness might be caused by a microbe or by maleficence or by both. An illness might be treated by doctors or voodoo priests or "leaf doctors" or by prayer or any combination of these. The extent to which Anita believed in each of these modalities remains unclear; she had recourse to all of them.

Differences in the responses of caregivers to Robert and Anita—such as whether to inform them of their diagnosis or undertake terminal care as a family or a community responsibility—also reflect the ego-centered orientation in North American cities and the more sociocentric orientation in the Haitian village. An ironic twist is that it is in the impersonal therapeutic setting of North American health-care institutions that concern for the patient's personhood is articulated. It is, however, a cool bioethical attention to abstract individual rights rather than a validation of humane responses to concrete existential needs. Perhaps this cultural logic—of medicine as technology, of individual autonomy as the most inviolable of rights, and so

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of individuals as responsible for most of the ills that befall them—helps us to understand how Robert's lonely death, so rich in all the technology applied to his last hours, could be so poor in all those supportive human virtues that resonate from the poverty-stricken village where Anita died among friends.

A core clinical task would seem to be helping patients to die a decent death. Although we agree that "the unthinking repetition of the notion that everyone dies from AIDS denies both the reality of—but more importantly the possibility of—our survival,"[9] admitting hope into the picture does not change the fact that death is a central reality for persons with AIDS. Yet out of all the aspects of AIDS that receive public attention—and public funding—in North America or internationally, this reality is often avoided or denied. For all the millions of words spilled on the denial of death in our society and the various psychotechniques advertised to aid us to overcome this societal silence, AIDS testifies vividly that our secular public culture is simply unable to come to terms with mortality. Biomedicine, lacking an eschatology or any other way of giving meaning to death but abounding in algorithms and technological apparatus to maintain life, casts death as the arch enemy. In a critical review of contemporary biomedicine's misapplication of technology, Lewis Thomas observes that "dying is regarded as the ultimate failure, something that could always be avoided or averted if only the health-care system functioned more efficiently."[10]

A final question might be asked in examining the stories of Robert and Anita: just how representative are they of the millions already exposed to HIV? As a middle-class, white gay male, Robert is thought by many to be a "typical victim of AIDS." But he is becoming increasingly less typical in the United States, where the epidemic is claiming more and more blacks and Hispanics, and Robert would not be sociologically representative of the typical AIDS patient in much of the rest of the world. In many Third World settings, sex differences in the epidemiology of HIV infection are unremarkable: in Haiti, for example, there is almost parity between the sexes. More importantly, most people with AIDS are not middle-

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class and insured. All this points to the fact that the virus that causes AIDS might exact its greatest toll in the Third World.

## AIDS IN GLOBAL CONTEXT

Although the pandemic appears to be most serious in North America and Europe, per capita rates reveal that fully seventeen of the twenty countries most affected by AIDS are in Africa or the Caribbean. Further, although there is heartening evidence that the epidemic is being more effectively addressed in the North American gay community, there is no indication that the spread of HIV has been curbed in the communities in which women like Anita struggle. Parts of Africa, especially, are feared to be destined for major upheavals due to AIDS. Although early reports of high HIV seroprevalence were clearly based on faulty research, even recent and revised estimates remain grim: "In urban areas in some sub-Saharan countries, up to 25% of young adults are *already* HIV carriers, with rates among those reporting to clinics for sexually transmitted diseases passing 30%, and among female prostitutes up to 90%."[11] In other words, the countries most affected are precisely those that can least afford it.

For example, the cities of New York and Kinshasa are faced with epidemics of roughly similar proportions: the annual incidence among New York adults has been recently estimated to be 110 per 100,000 men and 12 per 100,000 women; the annual incidence among men *and* women in Kinshasa, at 55 to 100 per 100,000. The similarities stop there, however: the per capita income of Zaire is approximately 1 percent of that of the United States. Kinshasa is home to the sole large teaching hospital in all of Zaire, a nation of almost 32 million; the New York metropolitan area alone can boast dozens of comparable facilities. It was recently estimated that the cost of providing ten Kinshasa AIDS patients with care comparable to that delivered in New York would exceed the annual budget of the African hospital—and physicians there are diagnosing up to fifteen new AIDS cases per day.[12]

An epidemic that cripples Kinshasa cripples the nation, as the city is the nexus of Zaire's political and economic activity. In spite of federal sluggishness in responding to the epidemic, it should be noted that New York City will receive a substantial amount of the 1 billion federal dollars to be allocated in 1989 for research on and treatment

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of HIV infection. This sum is greater than three times the size of Zaire's total foreign assistance in 1987. One group of development economists has projected that, by 1995, "the annual loss to Zaire's economy due to premature deaths from AIDS will be eight percent of the country's gross national product (GNP), or $350 million if measured against Zaire's 1984 GNP."[13] As striking a contrast as this is, a recent report reminds us that the situation is even worse in other countries: "Zambia, Rwanda, Haiti and Uganda are already finding AIDS from 20–100 times more of an economic burden than in the United States."[14]

These figures also remind us that AIDS has felled many like Anita—the poor, women of color, victims of many sorts of oppression and misfortune. Although heterosexual contact seems to be the means of spreading in many instances, not all who contract the disease are "promiscuous," a label that has often offended people in Africa, Haiti, and elsewhere. *Promiscuous* fails utterly to capture the dilemmas of millions like Anita. In an essay entitled "The Myth of African Promiscuity," one Kenyan scholar refers to the " 'new poor': the massive pool of young women living in the most deprived conditions in shanty towns and slums across Africa, who are available for the promise of a meal, new clothes, or a few pounds."[15]

Equally problematic, and of course related, is the term *prostitute*. It is often used indiscriminately to refer to a broad spectrum of sexual activity. In North America, the label has been misused in investigations of HIV seroprevalence: "the category *prostitute* is taken as an undifferentiated 'risk group' rather than as an occupational category whose members should, for epidemiological purposes, be divided into IV drug users and nonusers—with significantly different rates of HIV infection—as other groups are."[16] A more historical view reminds us that prostitutes have often been victims of scapegoating and that there has long been more energy for investigation of the alleged moral shortcomings of sex workers than for the economic underpinnings of their work.

In his study *The African Poor*, John Iliffe writes of "subsistence prostitution by women driven by poverty. . . . Many Hausa *karuwai* were forlorn women making a poor living, while Kinshasa's *vedettes* were few compared with its despised *chambres d'hôtel*, one of whom told an anthropologist, 'I am a woman and I have no learning: what work is there for me except prostitution?' "[17] Iliffe cites the work of

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Dirasse in the Amhara, where of those interviewed, "40 per cent said lack of employment was their chief reason for becoming prostitutes, 30 per cent cited divorce, and 13 per cent said they wanted to improve their income." As one of the women informed Dr. Dirasse, "During the day we wear our old clothes and go begging. At night we go out with men."[18]

The implications of this sort of comparative exercise, which remains a cornerstone of social anthropology, are manifold. The differences speak directly to those who would apply imported models of prevention to rural Haiti or Africa or any other Third World setting. A substantial public-health literature, reflecting the fundamentally interventionist perspective of that discipline, is inarguably necessary in the midst of an epidemic without cure or promising treatment. The same must be true for the burgeoning biomedical literature on AIDS. But with what consequences have these disciplines ignored the issue of AIDS as suffering? Whether reduced to parasite-host interactions or to questions of shifting incidence and prevalence among risk groups, AIDS has meant suffering on a large scale, and this suffering is not captured in these expert discourses on the epidemic.

How well has anthropology (or any other of the human sciences) done in filling this gap? The discipline has a long tradition of taking seriously the "native's point of view," and medical anthropology continues this tradition. But much of the new literature on AIDS has resulted, curiously, in a tendency to ignore how these meanings operate in people's lives. One person with AIDS put it bluntly:

> Anthropologists of our tristes tropiques have accumulated a considerable store of information and conclusions about our genes and our mores, our mode of socialization and our myths, but in so doing, they've lost sight of our humanity.[19]

Much the same accusation could be leveled against psychiatrists, psychologists, and the experts in the ethical and legal aspects of medicine who have contributed to the literature on AIDS: the special professional preoccupation with technique has quantified the disease and operationalized the variables in our response to it; the person, *the sufferer*, and his or her intimate circle are left invisible.[20] Thus, demoralization and despair resulting from living with a terminal condition become DSM-III

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depression; suffering, so entified, is rendered meaningless and provided with a chemotherapeutic solution.

Even more striking has been a failure to connect personal illness meanings with larger political and social systems. The case of Anita is instructive in this regard. When she insisted that she "tell the story from the beginning," it was because she construed the key events of her life as related to each other and leading consequentially to her illness. Even an event that took place years before her birth—the flooding of the valley in which her parents lived—was regarded as necessary to the narrative she was elaborating as she slowly died of AIDS. We have heard many Haitians speak of AIDS as an unsurprising addendum to the long list of catastrophes visited upon them by external forces.

The meaning of suffering in such a context is distinctive not only on account of different beliefs about illness and treatment responses but because of the brute reality of grinding poverty, high child and maternal mortality, routinized demoralization and oppression, and suffering as a central part of existence. The response to AIDS in such settings must deal with this wider context of human misery and its social sources. Surely it is unethical—in the broadest sense, if not in the narrow technical biomedical limits to the term—for international health experts to turn their backs on the suffering of people with AIDS in the Third World and to concentrate solely on the prevention of new cases.

## DEALING WITH AIDS AS SUFFERING

To what practical suggestions does a view of AIDS as human suffering lead? In the field of AIDS research, there is widespread agreement that the molecular biology of retroviruses, the development of a vaccine, and immunologic research that would underpin effective therapy top the list of research priorities. The list of eloquent advocates of this work includes some of the world's most influential scientists. Similarly, we need hardly add our voices to the chorus calling for more ambitious education programs. Prevention remains the sole effective means of controlling the spread of HIV. But we are concerned about another key dimension of the epidemic, one that is revealed not by diagnostic tests or by survey instruments but by the perspective advanced in this essay. Conceiving the syndrome as

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human suffering brings into relief a number of points too often dismissed as secondary.

*Suffering Compounded by Inappropriate Use of Resources*

The majority of all medical-care costs for AIDS patients is generated by acute inpatient care. In many ways, however, infection with HIV is more like a chronic disease. Based on cases of transfusion-associated HIV transmission in the United States, the mean time between exposure to the virus and the development of AIDS is over eight years. This period may well be lengthened by drugs already available. And as the medical profession becomes more skilled at managing the AIDS condition, the average time of survival of patients with the full-blown syndrome will also be extended. For many with AIDS, outpatient treatment will be both more cost-effective and more humane. For the terminally ill, home or hospice care may be preferred to acute-care settings, especially for people who "just want to be kept clean." Helping patients to die a decent death was once an accepted aspect of the work of health professionals. It must be recognized and appropriately supported as a core clinical task in the care of persons with AIDS.

Elsewhere, the second author of this paper has proposed that, for patients with chronic illness, routine biomedical treatment should be complemented by humane care that affirms the illness experience and its meaning.[21] Certain practical clinical strategies can, when proffered with the attitude of compassion for illness as an enduring burden and trial of the human spirit, improve health care for those who cannot be cured.

Not a small component of humane care for people with AIDS is soliciting their stories of sickness, listening to their narratives of the illness, so as to help them give meaning to their suffering. Restoring this seemingly forgotten healing skill will require a transformation in the work and training of practitioners and a reorganization of time and objectives in health-care delivery systems. Social commentator Susan Sontag would have us go a step further, inasmuch as she regards it as necessary for healing that we publicly resist that societally imposed rhetoric that accuses, discredits, and injures the afflicted.[22]

The practitioner should initiate informed negotiation with alternative lay perspectives on care and provide what amounts to brief

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medical psychotherapy for the threats and losses that make chronic illness so difficult to bear. But such a transformation in the provision of care will require a significant shift in the allocation of resources, including a commitment to funding psychosocial services as well as appropriate providers—visiting nurses, home health aides, physical and occupational therapists, general practitioners, and other members of teams specializing in long-term, outpatient care. A bright light is the increasing attention being given to the provision of sophisticated counseling services for those who are tested seropositive and for those diagnosed with AIDS.[23]

*Suffering Magnified by Discrimination*

In a recent study of the U.S. response to AIDS, the spread of HIV was compared to that of polio, another virus that struck young people, triggered public panic, and received regular attention in the popular media. "Although these parallels are strong," notes the author, "one difference is crucial: there was little early sympathy for victims of AIDS because those initially at risk—homosexual men, Haitian immigrants, and drug addicts—were not in the mainstream of society. In contrast, sympathy for polio patients was extensive."[24] This lack of sympathy is part of a spectrum that extends to hostility and even violence, and that has led to discrimination in housing, employment, insurance, and the granting of visas.[25] The victims of such discrimination have been not only people with AIDS or other manifestations of HIV infection but those thought to be in "risk groups."

In some cases, these prejudices are only slightly muted in clinical settings. In our own experience in U.S. hospitals, there is markedly more sympathy for those referred to as "the innocent victims"—patients with transfusion-associated AIDS and HIV-infected babies. At other times, irrational infection-control precautions do little more than heighten patients' feelings of rejection. Blame and recrimination are reactions to the disease in rural Haiti as well—but there the finger is not often pointed at those with the disease.

Although the President's Commission on AIDS called for major coordinated efforts to address discrimination, what has been done has been desultory, unsystematic, and limited in reach. While legislation is crucial, so too is the development of public-education programs that address discrimination and suffering. As the epidemic

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spreads, panic may yet erode the commendable professional, bureaucratic, and political resistance to mandatory testing for all, to quarantine, and to the exercise of brutal force in response to what is now being called by some a threat to national and international security.

*Suffering Augmented by Fear*

Underlying at least some of the discrimination, spite, and other inappropriate responses to AIDS is fear. We refer not to the behavior-modifying fear of "the worried well" but to the more visceral fear that has played so prominent a role in the epidemic. It is fear that prompts someone to refuse to get into a taxi driven by a Haitian man; it is fear that leads a reporter to wrench her hand from that of a person with AIDS; it is fear that underpins some calls for widespread HIV-antibody testing, and fear that has led some health professionals to react to patients in degrading fashion. The fact that so much of this fear is "irrational" has thus far had little bearing on its persistence.

Dissemination of even a few key facts—by people with AIDS, leaders of local communities, elected officials and other policy-makers, teachers, and health professionals—should help to assuage fear. HIV is transmitted through parenteral, mucous-membrane, or open-wound contact with contaminated blood or body fluids and not through casual contact. Haitians have no more risk of contracting the virus than do the citizens of any other nation and should no longer be considered risk prone by the U.S. Centers for Disease Control or any other official body. Indiscriminate HIV-antibody testing is more likely to heighten fear than to diminish it, especially in low-risk populations, where approximately half of all repeatedly reactive antibody tests will be falsely positive.[26] Although the risk of transmission of HIV to health-care professionals is not zero, it is extremely low, even after percutaneous exposure (studies show that, of more than 1,300 exposed health-care workers, only four seroconverted[27]). These facts are the province of all persons in positions of public responsibility and are our best protection against what the World Health Organization has termed "the other AIDS epidemic," that of "unnecessary suffering for the general population, including the HIV

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seropositive and people with AIDS caused, not by biological, but by socially determined, factors."[28]

*Suffering Amplified by Social Death*

In several memoirs published in North America, persons with AIDS have complained of the immediate social death their diagnosis has engendered. "For some of my friends and even family, I was dead as soon as they heard I had AIDS," a community activist informed us. "That was over two years ago." Even asymptomatic but seropositive individuals, whose life expectancy is often better than that of persons with most cancers and many common cardiovascular disorders, have experienced this reaction. Many North Americans with AIDS have made it clear that they do not wish to be referred to as victims: "As a person with AIDS," writes Navarre, "I can attest to the sense of diminishment at seeing and hearing myself referred to as an AIDS victim, an AIDS sufferer, an AIDS case—as anything but what I am, a person with AIDS. I am a person with a condition. I am not that condition."[29]

It is nonetheless necessary to plan humane care for persons with a chronic and deadly disease—"without needlessly assaulting my denial," as a young man recently put it. The very notion of hospice care will need rethinking if its intended clients are a group of young and previously vigorous persons. Similarly, our cross-cultural research has shown us that preferred means of coping with a fatal disease are shaped by biography and culture. There are no set "stages" that someone with AIDS will go through, and there can be no standard professional response. For a field beset by recent attacks for its lack of humanism, biomedicine will need all the support it can get from other helping professions and from concerned communities and patient advocacy groups in order to effectively address the stigma, spoiling of identity, shame, humiliation, and outright rejection that has all too often been the ordeal of people with AIDS. These problems will require major changes in the education of health-care providers at all levels but also in the moral education of all of us.

*Suffering Generated by Inequities*

AIDS is caused, we know, by a retrovirus. But we need not look to Haiti to see that inequities have sculpted the AIDS epidemic. The disease, it has been aptly noted, "moves along the fault lines of our

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society."[30] Of all infants born with AIDS in the United States, approximately 80 percent are black or Hispanic.[31] Most of these are the children of IV drug users, and attempts to stem the virus may force us to confront substance abuse in the context of our own society. For as Robert Gallo and Luc Montagnier assert, "efforts to control AIDS must be aimed in part at eradicating the conditions that give rise to drug addiction."[32]

There are inequities in the way we care for AIDS patients. In the hospital where Robert died, AZT—the sole agent with proven efficacy in treating HIV infection—is not on formulary. Patients needing the drug who are not in a research protocol have to send someone to the drugstore to buy it—if they happen to have the $10,000 per year AZT can cost or an insurance policy that covers these costs. The same goes for aerosolized pentamidine, a treatment for the most common of opportunistic infections that strike North Americans with AIDS. Such factors may prove important in explaining the striking ethnic differences in average time of survival following diagnosis of AIDS. In one report it was noted that, "while the average lifespan of a white person after diagnosis is two years, the average minority person survives only 19 weeks."[33]

From rural Haiti, it is not the local disparities but rather the international inequities that are glaring. In poor countries, drugs like AZT are simply not available. The harvest of the last five years of clinical and basic research has been spread among the wealthy developed nations. (In fact, if AIDS had not affected these nations, experience with the major tropical disorders suggests it is highly unlikely that AIDS would have attracted the attention *and* funds that it has.) Because adequate resources have not been made available for screening, transfusion-associated transmission of HIV continues apace in many of the countries hit hardest by AIDS—this when the majority of those infected with the virus are thought to live in the Third World. As noted above, the AIDS pandemic is most severe in the countries that can least afford a disaster of these dimensions. A view of AIDS as human suffering forces us to lift our eyes from local settings to the true dimensions of this worldwide tragedy.

Compassionate involvement with persons who have AIDS may require listening carefully to their stories, whether narratives of suffering or simply attempts to recount their lives. Otherwise, as Anita pointed out, we may understand nothing at all. When we do

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understand what representatives of minority and non-Western communities are telling us—namely, that AIDS emerges from and contributes to vicious social cycles of human misery—will we demand that domestic and international efforts at AIDS control address causes and consequences that lie outside the scope of traditional medical intervention? Past and current responses to the AIDS pandemic suggest that we are unlikely to do so. When we understand what people with AIDS are telling us about their experiences—the denial of suffering and death, the impersonal bureaucratization of care, the recourse to technological "fixes," and our failure to lighten the degrading burden of stigma—will we appropriate from these plangent complaints their accusation against the now dominant definitions of reality and business-as-usual responses to human misery? If history is any kind of guide, probably not. In this sense, perhaps our response to AIDS will be for future historians and the generations that follow us a telling indicator of the constraints on the human spirit in our times.

ENDNOTES

We thank Carla Fujimoto, Haun Saussy, and Barbara de Zalduondo for their thoughtful comments on this essay.

[1]Emmanuel Dreuilhe, *Mortal Embrace: Living with AIDS* (New York: Hill and Wang, 1988), 20.

[2]Susan Sontag,"AIDS and Its Metaphors," *New York Review of Books* 35 (16) (27 October 1988): 88–99.

[3]The first three of the four quotations cited here are the voices of persons with AIDS who attended the Third International Conference on AIDS, held in Washington, D.C. in June 1987. Their comments are published passim in 4 (1) (Winter/Spring 1988) of *New England Journal of Public Policy*. All subsequent unreferenced quotations are from tape-recorded interviews accorded the first author.

[4]R. S. Gottfried, *The Black Death: Natural and Human Disaster in Medieval Europe* (New York: Free Press, 1983).

[5]All informants' names are pseudonyms, as are "Do Kay" and "Ba Kay." Other geographical designations are as cited.

[6]Philip Slater, *The Pursuit of Loneliness: American Culture at the Breaking Point* (Boston: Beacon Press, 1970), 49, 51.

[7]Dreuilhe, 20.

[8]George Whitmore, *Someone Was Here: Profiles in the AIDS Epidemic* (New York: New American Library, 1988), 26.

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[9]Remarks of Michael Callen to the annual meeting of the American Public Health Association, Las Vegas, Nevada, 1986, reprinted in "PWA Coalition Portfolio," in *AIDS: Cultural Analysis/Cultural Activism*, ed. Douglas Crimp (Cambridge: MIT Press, 1988), 163.

[10]Lewis Thomas, "On the Science and Technology of Medicine," reprinted in *Dædalus* 117 (3) (Summer 1988):299–316.

[11]Renée Sabatier, *Blaming Others: Prejudice, Race, and Worldwide AIDS* (Philadelphia: New Society Publishers, 1988), 15.

[12]Lori Heise, "AIDS: New Threat to the Third World," *World Watch* 1 (1) (1988): 19–43.

[13]Ibid., 25.

[14]Sabatier, 15–16.

[15]Professor Aina cited in Sabatier, 80.

[16]Jan Zita Grover, "AIDS: Keywords," in *AIDS: Cultural Analysis/Cultural Activism* (Cambridge: MIT Press, 1988), 25–26.

[17]John Iliffe, *The African Poor: A History* (Cambridge: Cambridge University Press, 1987), 184.

[18]Ibid., 185.

[19]Dreuilhe, 4.

[20]Eric J. Cassel, "The Nature of Suffering and the Goals of Medicine," *New England Journal of Medicine* 306 (11) (March 1982):641–45.

[21]Arthur Kleinman, *The Illness Narratives: Suffering, Healing, and the Human Condition* (New York: Basic Books, 1988).

[22]Sontag.

[23]S. Perry and J. C. Markowitz, "Counseling for HIV Testing," *Hospital and Community Psychiatry* 39 (7):731–39.

[24]Sandra Panem, *The AIDS Bureaucracy* (Cambridge: Harvard University Press, 1988), 15.

[25]See Sabatier for an overview of AIDS-related discrimination. As regards Haiti and Haitians, see Paul Farmer, "AIDS and Accusation: Haiti, Haitians, and the Geography of Blame," in *Cultural Aspects of AIDS: Anthropology and the Global Pandemic* (New York: Praeger, in press). The degree of antipathy is suggested by a recent *New York Times*-CBS News poll of 1,606 persons: "Only 36 percent of those interviewed said they had a lot or some sympathy for 'people who get AIDS from homosexual activity,' and 26 percent said they had a lot or some sympathy for 'people who get AIDS from sharing needles while using illegal drugs' " (*New York Times*, 14 October 1988, A12).

[26]See, for example, the figures advanced by the Infectious Diseases Society of America, in "The Acquired Immunodeficiency Syndrome (AIDS) and Infection with the Human Immunodeficiency Virus (HIV)," *The Journal of Infectious Diseases* 158 (2):273–85.

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[27]Infectious Diseases Society of America, 276.

[28]Ronald Frankenberg, "AIDS and Anthropologists," *Anthropology Today* 4 (2) (April 1988).

[29]Max Navarre, "Fighting the Victim Label," in *AIDS: Cultural Analysis/Cultural Activism* (Cambridge: MIT Press, 1988), 143.

[30]Mary Catherine Bateson and Richard Goldsby, *Thinking AIDS: The Social Response to the Biological Threat* (Reading, Mass.: Addison-Wesley, 1988), 2.

[31]Samuel Friedman, Jo Sotheran, Abu Abdul-Quadar, Beny Primm, Don Des Jarlais, Paula Kleinman, Conrad Mauge, Douglas Goldsmith, Wafaa El-Sadr, and Robert Maslansky, "The AIDS Epidemic among Blacks and Hispanics," *The Milbank Quarterly* 65, suppl. 2 (1987):455–99.

[32]Robert Gallo and Luc Montagnier, "AIDS in 1988," *Scientific American* 259 (4) (October 1988):48.

[33]Sabatier, 19.

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# Abstract of "The Epidemiology and Transmission Dynamics of HIV-AIDS"

This essay discusses how the transmission of HIV infection, and thence AIDS disease, depends on various biological and social factors, which can differ within and between different groups. It explains, for example, the difference between knowing that HIV can be transmitted by heterosexual sex (which it can) and knowing whether there will be a "third wave" epidemic of HIV in developed countries, transmitted along purely heterosexual chains (which at present seems unlikely but remains uncertain). We emphasize the current uncertainties and lack of adequate data about patterns of infectiousness over the long and variable incubation period between HIV infection and AIDS disease (and whether, indeed, AIDS always develops), about the probability that an infectious individual will actually infect a partner, and about the patterns in rates of acquiring new partners in specific groups (male homosexuals, heterosexuals, needle sharers, all in particular places at particular times); we show how these biological and social factors weave together to determine whether a self-sustaining HIV epidemic can or cannot spread within a specified group. The result is a chapter that—however much we have striven toward simplicity and avoided mathematical detail—is more technical and more analytic than most others in this issue. But these basic epidemiological facts are an essential basis for any discussion of the ethical, social, and political dimensions of HIV-AIDS, and so we urge readers to have the patience to struggle through the thickets of a presentation that some of our colleagues at the authors' conference found difficult.

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*Robert M. May, Roy M. Anderson, and Sally M. Blower*

# The Epidemiology and Transmission Dynamics of HIV-AIDS

By FEBRUARY 1988, 133 countries had reported cases of AIDS to the World Health Organization, and the total number of reported cases had more than doubled between December 1986 and December 1987. It is about five years since the virus that causes AIDS, HIV, was first discovered, and in that time a great deal has been learned about the molecular biology of the virus and its interactions with the immune system. Paradoxically, our knowledge about the molecular structure of the virus (a nearly unimaginable abstraction to most of us) is not matched by similarly precise knowledge of many of the seemingly more mundane biological and behavioral factors that govern the overall transmission of infection within a given group. This is the situation partly because the questions of molecular biology can be brought into the laboratory and studied in such a way that answers emerge in weeks or months; for many of the epidemiological questions, we need to study large groups of people over time intervals comparable with the long, variable, and usually asymptomatic incubation time from acquiring HIV infection to manifesting AIDS disease (which on average may be seven to eight years or more).

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To put it another way, the true dimension of the AIDS problem in any country or group is hard to define because that which is most easily observable—the occurrence of AIDS—is but a small part of the HIV epidemic. The true epidemic, namely all those infected and infectious with the HIV virus, is essentially invisible because most infected individuals show no symptoms. In these circumstances, epidemiologists can play an important part in defining the information we need, in designing studies and surveys aimed at acquiring this information, and in illuminating the often complex relations between the biology of individuals and the biology of populations.

An understanding of the transmission dynamics of HIV can help us anticipate the magnitude of the call on medical services and hospital beds, or even the impact on demographic trends in countries where heterosexually transmitted HIV-AIDS is now widespread. Such understanding can also help us evaluate the likely effects of different kinds of intervention. Among the questions that arise are: How likely is it that infection will be transmitted by a particular act (sharing a contaminated needle or a single sexual act of a specified kind)? How, precisely, is the likelihood of transmission affected by many repetitions of the act with the same infected partner? How effective are measures aimed at reducing transmission probabilities (sterilizing needles with bleach, use of condoms)? Are there identifiable characteristics of susceptible or infected individuals that make transmission more or less likely?

Of particular relevance to a discussion of the population biology of any organism is its basic reproductive rate, $R_0$. For a directly transmitted viral or bacterial infection, $R_0$ is essentially the number of infections produced, on average, by an infected individual in the early stages of the epidemic, when virtually all contacts are susceptible. If $R_0$ exceeds unity ($R_0>1$), each infection has, as it were, more than one offspring and we have an expanding chain reaction or epidemic of infection. If, on the other hand, $R_0$ is less than unity ($R_0<1$), the infection cannot sustain itself; if infected individuals are introduced, there will be short chains of infection and subsequent disease and suffering, but a self-sustaining epidemic is not possible. The larger the value of $R_0$, the shorter the time it takes for the number of cases to double.

For HIV-AIDS, this basic reproductive rate, $R_0$, can be seen to depend on the average probability that an infected individual will

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infect a susceptible partner over the duration of their relationship (we call this probability β) times the average number of new partners acquired per unit time within the specified risk category (we call this number c) times the average duration of infectiousness (called D): $R_0=\beta cD$. Although there are substantial problems associated with what exactly is meant by *average* in the above statement, there is no doubt that current data are not sufficient to assign accurate values to any one of these three components of the basic reproductive rate. We do know that $R_0$ must have exceeded unity among homosexual males in large cities in many developed countries in the early 1980s (possibly it still does) and that $R_0$ currently exceeds unity among intravenous (IV) drug abusers in the northeastern United States and other places. Likewise, $R_0$ now exceeds unity along heterosexual chains of transmission in large parts of central Africa. But, as we shall see below, the uncertainties are such that in the United Kingdom, the United States, and other developed countries, we cannot be sure whether $R_0$ is above or below unity among particular groups of heterosexuals (who have no other kinds of exposure to HIV). Returning to the above equation, we emphasize that $R_0$, thus defined, depends both on the fundamental biology of the HIV virus (which affects the duration of infectiousness, D, for example) and on behavioral factors such as rates of acquiring new sexual partners, and the use or not of condoms; $R_0$ can thus differ from one risk group to another and change over time in response to behavioral changes.

An alternative approach is to look beyond quantities such as β, c, and D, which characterize transmission among individuals, and focus on the fraction of a given group that is seropositive for HIV or on other quantities that characterize transmission dynamics at the population level. By monitoring changes in seropositivity levels over time, we can—if the data are adequate—see whether the infection is spreading within a defined group and also make short-term predictions. For long-term predictions, however, we must understand the underlying processes (as characterized by β, c, D, etc.); the nonlinearities inherent in epidemiological processes can cause the dynamics to change in qualitative ways as the epidemic progresses. A less conventional use for mathematical models of the epidemiology of HIV-AIDS is to work backwards to infer the magnitude of individual-level parameters, such as β, c, or D, from overall population-level data, such as trends in seropositivity.

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In what follows, we first summarize the main ways in which HIV-AIDS has spread so far. Then we survey what is known about the duration of infectiousness, D, about the probabilities of infecting a partner, β, and about the rate of acquiring new partners, c. Data on HIV seropositivity among various groups in various countries are then reviewed. In all this, the emphasis is on what we need to know in order to understand the epidemic and on ways we may go about acquiring this knowledge. Discussions of the ethical, social, legal, political, and other dimensions of the epidemic must be grounded in an understanding of epidemiological facts; if not so grounded, such discussions run the risk of being vacuous. We conclude with some thoughts about how careful we need to be in reconciling the rights of individuals to privacy with our need to understand the transmission dynamics of HIV, in order that we may act effectively.

## GROUPS AT RISK FOR HIV-AIDS

Before discussing the various biological and social factors that determine the basic reproductive rate, $R_0$, for HIV, we need to recognize that these factors can vary greatly both between and within particular groups. In sub-Saharan Africa, HIV-AIDS appears to be mainly transmitted by sexual contacts among heterosexuals.[1] In developed countries, homosexual and bisexual males account for most cases of AIDS (around 65 to 85 percent or more). Intravenous drug abusers also constitute a major fraction of AIDS cases in developed countries, with significant variations within and between countries; IV drug abusers make up about half the recently reported AIDS cases in northeastern regions of the United States.

HIV infections and AIDS cases resulting from blood transfusions in general, and among hemophiliacs in particular, amounted to a small fraction of the total in earlier years. In developed countries there have been very few, if any, new infections in these categories following the introduction of screening and testing of blood supplies. This transmission route is still open in some developing countries, however, and its role in the overall transmission pattern in such countries remains somewhat uncertain. Although transmission-associated AIDS cases are relatively few, we shall see below that they play a disproportionate part in our current understanding of the epidemiology of HIV; this is partly because for such cases it is usually

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possible to infer when HIV infection was acquired by blood transfusion (whereas, as we have already noted, the date of infection is not commonly known for individuals in other groups).

HIV-AIDS can be transmitted to the offspring of infected mothers, and these pediatric AIDS cases are increasing wherever AIDS is reported. Although very uncertain, current estimates are that perhaps 30 to 50 percent or more of the children born to infected mothers will die of AIDS in their first few years.

The age-specific incidence of AIDS cases in both developed and developing countries seems to rule out any significant transmission of HIV infection by insect vectors or by contaminated needles in public-health programs. Were it otherwise, one would expect to see more cases in the five- to fifteen-year-old range (although it is conceivable that multiple use of vaccination needles in developing countries is concentrated within age cohorts and thus does not propagate HIV among children so long as the prevalence remains very low in this age group; there is room for further empirical and theoretical study of this question).

These facts lead us to confine our remarks to the transmission dynamics of HIV-AIDS among homosexual males in large cities in the United Kingdom, the United States, and other developed countries, and among heterosexuals in Africa. Many of the same considerations apply to IV drug users (although here there seems to be virtually no quantitative information about rates of sharing needles). Public-health planning will eventually require complex epidemiological models that embrace all the transmission routes discussed above and that assign magnitudes to the parameters characterizing linkages among different categories.[2] Given our current state of ignorance about many of the basic aspects of transmission, we think such models are premature as yet; indeed, their very complexity may convey a beguiling, but unjustified, illusion of accuracy (which is not the modelers' intention).

The different patterns in various countries, and within various regions and groups in any one country, are reflected in ratios of AIDS cases among men to AIDS cases among women. The current overall incidence of AIDS in the United States is thirteen times greater for males than for females,[3] which accords with the ratios of 14:1 to 20:1 found in European countries.[4] As summarized in Table 1, however, studies among particular groups in the United States give

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lower ratios, which seems reasonable given the nature of the groups. In Africa, by contrast, the sex ratio of AIDS cases runs around 1:1,

TABLE 1. Ratio of AIDS Cases or HIV Prevalence among Males to that among Females in some Studies in the United States

| Group | Statistic | Ratio of Men to Women |
|---|---|---|
| All AIDS cases | Cumulative number of reported AIDS cases through 1987 | 13.0 to 1 |
| Heterosexual adult and adolescent AIDS cases | Cumulative number assigned to this category of Centers for Disease Control data through 1987 | 2.9 to 1 |
| Military recruit applicants | Seroprevalance of HIV: data from Department of Defense, 1985–1988 | 5.5 to 1 |
| American Red Cross blood donors | Nationwide seroprevalence of HIV, 1986–1987: | |
| | First-time donors | 4.6 to 1 |
| | Repeat donors | 4.6 to 1 |
| Sentinel hospital patients in Midwest | Seroprevalence of HIV, unpublished CDC data | 2.3 to 1 |
| IV drug users | New York City, 1985 | 0.9 to 1 |
| IV drug users | Four cities in Connecticut, 1986–1987 | 1.2 to 1 |

Source: Department of Health and Human Services, *HIV Infections in the United States: A Review of Current Knowledge and Plans for Expansion of HIV Surveillance Activities*, report to the Domestic Policy Council (Washington D.C.: Department of Health and Human Services, 1987).

with perhaps a slight excess of female cases.[5] Other patterns will be discussed below, when we look at such information as exists about seropositivity levels in particular populations.

## INCUBATION AND INFECTIOUS PERIODS

Most epidemiological models for the spread of HIV assume some uniform level of infectiousness throughout the long and variable incubation period that elapses between HIV infection and the onset of AIDS. Information about this distribution of incubation intervals derives mainly from transfusion-associated AIDS cases,[6] although these could be unrepresentative of incubation periods in patients infected by needle sharing or by sexual activity, or indeed for patients in developing countries; it is reassuring that analyses of the limited

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amount of information that is available about homosexual males for whom the time point of seroconversion is known give roughly concordant answers.[7]

In particular, an analysis of 512 cases in which dates of transfusion and diagnosis of AIDS are known suggests the mean and median incubation periods are both between seven and eight years in patients older than twelve years (with the distribution of incubation intervals described by a Weibull distribution, such that the probability to develop AIDS at time $\tau$ after infection is $p(\tau)=a\tau^{\nu-1}\exp(-b\tau^{\nu})$, where a, b, and $\nu$ are constants).[8] In earlier studies, the estimated average incubation period has been disconcertingly close to the time span over which data are available, suggesting that the average could lengthen as more information accumulates. This most recent analysis, however, suggests that estimates of the average are settling to around seven to eight years. The average incubation interval is somewhat shorter in children (under twelve years) and for elderly people (above sixty years), and appears to be much less in infants who acquire infection from their mothers.[9]

Estimates of the fraction, f, of those infected with HIV who will go on to develop AIDS have increased with time. Rates of progression from HIV seropositivity to AIDS disease (which are derived largely from cohorts where the actual dates of seroconversion are not known) range from below 1 percent to above 12 percent per annum, with an average of around 5 percent to 7 percent per annum.[10] Current evidence suggests that 30 to 75 percent of infected individuals will have progressed to AIDS within six years. In the San Francisco City Clinic cohort study of 6,700 homosexual and bisexual men, 75 percent had been infected with HIV within eighty-eight months, and of these only 20 percent had remained completely asymptomatic.[11] It is increasingly being recognized that this fraction, f, may be essentially 100 percent, with the only uncertainty being the distribution of time to the development of disease.

Once AIDS is diagnosed, the average life expectancy of patients reported in recent studies in the United States[12] and in the United Kingdom[13] is approximately one year. Studies of survival in infants and children who acquired infection perinatally or by transfusion reveal shorter survival time, with an average of around eight months.[14]

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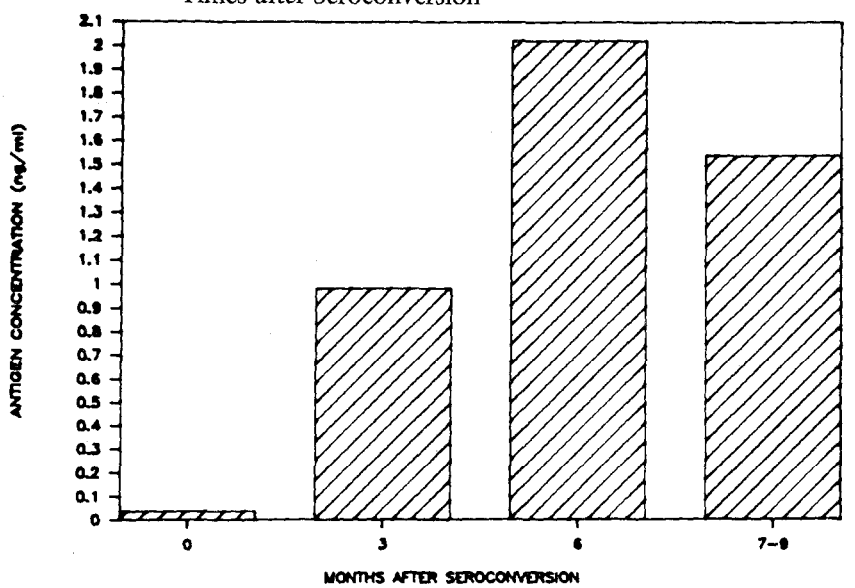
Epidemiological and clinical studies suggest that the infectiousness of individuals with HIV may fluctuate over the long and variable incubation period between infection and AIDS. Longitudinal studies of fluctuations in viral abundance, or in the concentration of HIV antigens in serum, cells, or semen, reveal great variability among patients, both in antigenemia (presence of detectable HIV antigens in the blood) and antibody titers.[15] A tentative hypothesis is that antigenemia rises to a peak during, or just before, primary HIV infection (Figure 1a), and then typically falls to very low levels—often

Figure 1a. Average Concentration of HIV Antigens in Serum Samples Taken from Homosexual Men Infected with HIV at Various Times after Seroconversion




Sample sizes: n = 11 at time 0; n = 8 at 3 months; n = 4 at 6 months; n = 4 at 7–9 months.

Source: J. Goudsmit and D. A. Paul, "Circulation of HIV Antigen in Blood according to Stage of Infection, Risk Group, Age, and Geographic Origin," *Epidemiology and Infection* 3 (1987):701–11.

undetectable by current methods—before beginning to rise again as symptoms of disease appear and the persistent generalized lymphadenopathy (broadly speaking, swollen lymph nodes) progresses to the AIDS-related-complex (ARC) stage, and finally to AIDS (Figure 1b). Patients who progress through this last step rapidly may have a detectable antigenemia throughout the entire incubation period.

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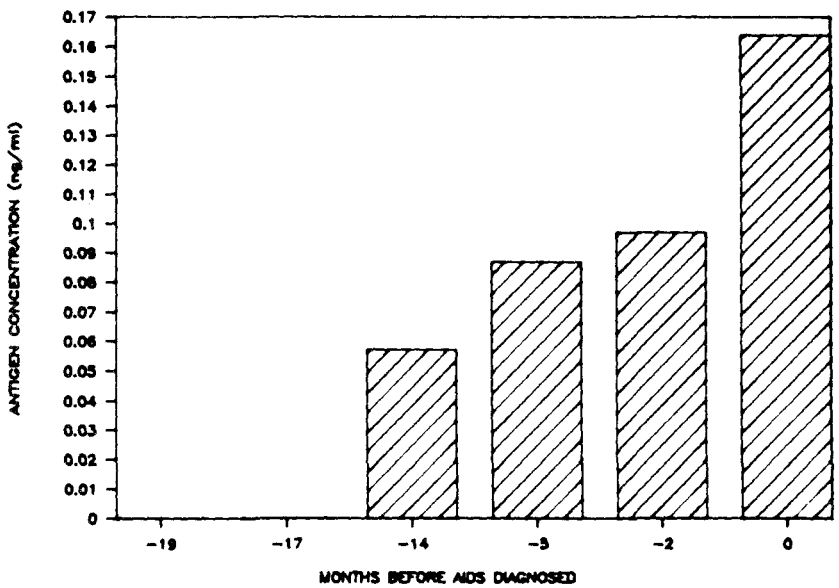
Concomitant with these changes, antibodies in relation to core antigens rise slowly, reach peak titers when antigenemia is undetectable or low, and then fall to very low levels as clinical disease develops (Figure 1c). Antibodies to envelop antigens appear to

Figure 1b. Antigen Concentrations at Specific Times (in Months) before Conversion to AIDS in Serum Samples Drawn from a Male Homosexual Patient




remain high, on average, throughout the incubation period following primary HIV infection.

There are practical problems in the quantification of antigen titers in serum samples, in the detection of the infected cells, and—most importantly—in relating antigen concentration in serum to infectiousness (because it takes no account of virus abundance in secretions and excretions). If, however, the two peaks in antigenemia are indeed associated with an early and a late peak in infectivity, then simple mathematical models for the transmission dynamics of HIV indicate that such variability of infectivity over the long average incubation period can have significant implications for interpreting temporal trends in the incidence of HIV seropositivity and AIDS cases.[16]

In the simplest case, the above relation between the basic reproductive rate, $R_0$, and the parameters, $\beta$, c, and D ($R_0=\beta cD$) will be

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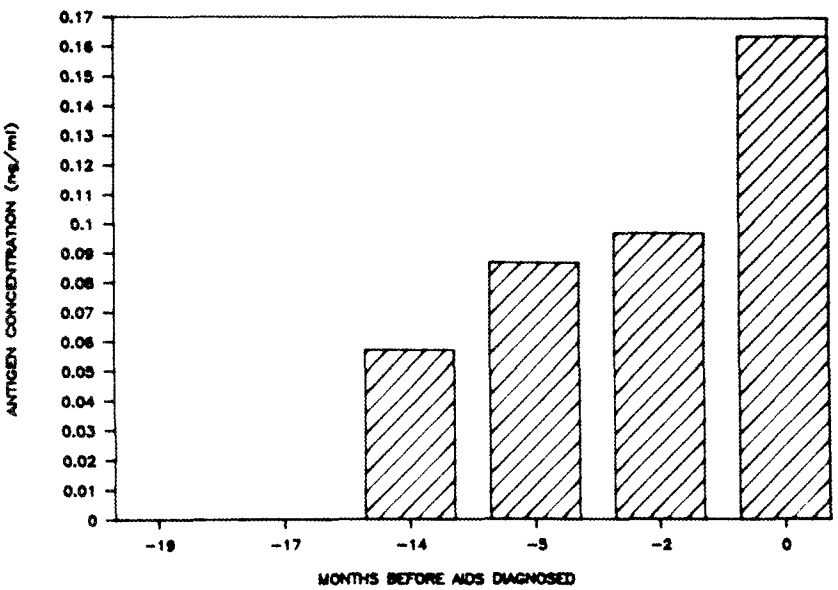


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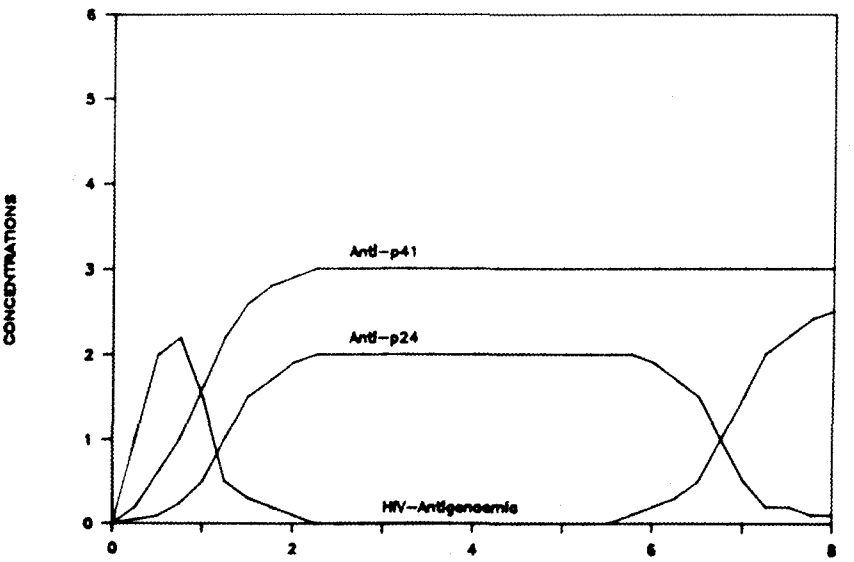
replaced by the somewhat more complicated relation $R_0=c(\beta_1 D_1+\beta_2 D_2)$. Here c is still the average rate at which new sexual (or needle-sharing) partners are acquired, and $\beta_1$ and $\beta_2$ are the trans-

Figure 1c. A Schematic Representation of Changes in Antigen (p24) and Antibody (p41) over the Interval from Infection to Development of AIDs




Average incubation = 8 years.

Source: R. M. Anderson and R. M. May, "Epidemiological Parameters of HIV Transmission," *Nature* 333 (1988):514–19.

mission probabilities (that is, the probabilities that an infected individual will infect an uninfected partner) associated with the early and late phases of infectivity, which are of average duration $D_1$ and $D_2$, respectively. This relation for $R_0$ says that, in the early stages of the epidemic (when most people are uninfected), each infected individual will, on average, produce new infections at a rate $\beta_1 c$ (corresponding to a transmission probability $\beta_1$ for each of the c new partners, per unit of time) over an average interval $D_1$ early in the course of his or her infection, and later on will produce additional new infections at a rate $\beta_2 c$ over an average interval $D_2$ during the second phase of infectiousness (as ARC and then AIDS itself develop). It can be seen that the exponential growth in the incidence of HIV infection within the population in the early stages of the epidemic will tend to be set by the average transmission probability in

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the first episode of infectivity (at the rate $\beta_1 c$), because infected individuals are typically producing these first-phase infections several years (on average something like six to seven years) before they produce second-phase infections concomitant with progression to ARC and AIDS. On the other hand, the fraction eventually infected will, in the long run, depend on $R_0$ and thus on both episodes of infectivity. These aspects of the "demography" of HIV infection have a direct analogy with more familiar features of human demography: in an HIV epidemic, early "births" have more effect than do later ones on population growth rates, but all births are relevant to the total of "offspring" (here meaning infected people).

The above discussion may appear to be intruding technicalities from the discourse of professional epidemiologists into what is intended as a general survey. But how we think about education programs and other interventions is necessarily colored by these complications. Were it true (as suggested, for example, by Bateson and Goldsby[17]) that infectiousness was mainly associated with the progression to ARC or "full-blown" AIDS, then we would have a situation where most infectious individuals actually were, or should be, aware of their infectious status. But the existence of an earlier phase (or phases) of infectiousness, coupled with the appreciation that infections earlier produced play a disproportionate part in the dynamics of the epidemic, leaves us with the more difficult situation where much—maybe most—of the exponentiating spread of infection is from individuals who may easily be unaware that they are infected with HIV, much less that they are infectious. Clearly, these two extremes present different settings for debates about ethical issues, and the epidemiological details have social implications. Moreover, at the level of epidemiological practicalities, the existence of two peaks in infectiousness can induce complex patterns of growth in the HIV epidemic curve and can thereby make it more difficult for us to draw conclusions from such data as are available. It should be emphasized, however, that we cannot yet be sure there are two peaks in infectiousness: not only is the connection between HIV-antigenemia and infectiousness uncertain, but there is great variability in the patterns of antigenemia observed in different patients over time. The picture is further complicated by hints that bursts of viremia can occur between primary HIV infection and the onset of AIDS disease, and by the fact that the simplest models mimicking the

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interaction between HIV and the immune system can generate such fluctuations as a consequence of chaotic dynamical behavior.[18]

In summary, we are getting closer to pinning down the average incubation period (along with its considerable variability) and to recognizing how large a fraction (possibly close to 100 percent) of HIV infectees will eventually go on to develop AIDS. But our knowledge about infectiousness over the long and variable incubation period is still rudimentary. Many different lines of investigation are needed. For one thing, studies directed toward molecular-biological understanding of the pathogenic effects of HIV (for instance, why there is a predominance of Kaposi's sarcoma or *Pneumocystis carinii* among all possible cancers and opportunistic infections) could lead to better understanding of the length and variability of the stages that eventually lead to the collapse of the immune system. For another thing, epidemiological studies that deliberately seek to identify the point of seroconversion and to follow the subsequent course of HIV antigenemia in individual cases are of great value; the problems inherent in the recruitment of individuals with known seroconversion dates are such that studies of this kind are likely to remain sparse and with small sample sizes. The considerable variability from person to person, both within and between groups, exacerbates these difficulties. In particular, we would like to see more work on whether or not there are any systematic differences in distributions of incubation times and/or infectiousness between geographical regions (e.g., Africa versus Europe) or between different risk groups within a region (e.g., infections acquired via homosexual sex versus IV drug abuse versus blood transfusion).

The degree to which all these uncertainties affect projections about the spread of HIV-AIDS within any particular group can be seen by returning to our earlier expression for the basic reproductive rate $R_0=\beta cD$, where—in some average sense—D stands for the duration of the infectiousness. If individuals are infectious throughout the entire incubation period (either at some roughly steady level or in chaotic bursts of viremia), then we would estimate D as characteristically around ten years. But if individuals are only infectious for a year or less following the original infection, and again for a brief period at the onset of AIDS, we would estimate D as more like one year. This translates into a factor-of-ten uncertainty in the estimate of

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the basic reproductive rate, $R_0$, quite apart from the uncertainties in $\beta$ and c, to which we now turn.

## PROBABILITY OF TRANSMISSION

When one considers the probability that an infected person will infect a susceptible sexual partner, one of two assumptions that are opposite extremes may be used. One assumption is that there is, on average, some constant transmission probability, $\delta$, per sexual contact, and that such probabilities compound independently and randomly (with $\delta$, of course, depending on the details of the sexual contact—e.g., whether oral, vaginal, or anal, or with or without a condom). The overall probability for an infected individual to infect a sexual partner then increases with the number of such contacts. This process of compounding the independent probabilities of transmission in each of several contacts (a so-called Poisson process) gives, on average, an overall transmission probability per partnership of approximately $1-\exp(-\delta n)$ after n contacts. The opposite extreme, which at first sight may seem less likely, is that the transmission probability is, on average, some constant for all partnerships of a given kind, roughly independent of the number of contacts.

The main sources of information about the probability of transmission are longitudinal studies of the likelihood of seroconversion for susceptible sexual partners of HIV-infected patients, such as monogamous partners of men or women infected either in the course of IV drug abuse or by transfusion of blood or blood products. The interpretation of such studies, however, is beset with many difficulties owing to the high variability in sexual practices and activity within small study populations, to problems in associating a transmission event with the length of time that the index case has harbored HIV (along with the time scale on which he or she will develop AIDS), and to the need to link the likelihood of transmission with highly variable quantitative measures of viral or antigen abundance, immunological parameters (CD4/CD8 cell ratio, CD4-cell depletion, and antibody titers) and clinical measures of disease status. Recent reviews suggest that the average transmission probability, $\beta$, for heterosexual partnerships is around 0.1 to 0.2 (uncertain by at least a factor of 2) in studies with moderate sample sizes.[19] These studies are summarized in Table 2, and it should be noted that many of them suffer from the

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TABLE 2. HIV Seroprevalence in Partners of Individuals Infected with HIV, Which Gives an Estimate of the Upper Limit to the Probability of Transmission

| Type of transmission and risk group | Size of sample | Country | Fraction seropositive |
|---|---|---|---|
| *Male to Female* | | | |
| Transfusion group* | 55 | United States | 0.18 |
| Mixed group, including bisexuals | 97 | United States | 0.23 |
| Army personnel | 18 | United States | 0.33 |
| IV drug users | 88 | United States | 0.48 |
| Mixed group, including bisexuals | 28 | United States | 0.50 |
| Patients from Africa | 38 | | 0.73 |
| Patients from Africa | 14 | | 0.71 |
| Hemophiliacs | 30 | | 0.03 |
| Hemophiliacs | 77 | United Kingdom | 0.04 |
| Hemophiliacs | 148 | France | 0.07 |
| Hemophiliacs | 21 | United States | 0.10 |
| Hemophiliacs | 40 | | 0.10 |
| Hemophiliacs | 24 | United States | 0.17 |
| Hemophiliacs | 33 | United States | 0.06 |
| Transfusion Group | 50 | United Kingdom | 0.16 |
| IV drug users | 48 | United Kingdom | 0.35 |
| *Female to Male* | | | |
| Transfusion group* | 25 | United States | 0.08 |
| Army personnel | 6 | United States | 0.33 |
| Patients from Africa | 10 | | 0.40 |
| IV drug users | 12 | | 0.58 |
| Mixed group | 17 | United States | 0.71 |
| *Male to Male* | | | |
| Male homosexuals | 35 | United Kingdom | 0.60 |
| Male homosexuals | 343 | United States | 0.10 |

*With the exception of the study by T. A. Peterman, R. L. Stoneburner, J. R. Allen, H. W. Jaffe, and J. W. Curran ("Risk of HIV Transmission from Heterosexual Adults with Transfusion-associated Infections," *Journal of the American Medical Association* 259 [1988]: 55–63), which is indicated on the table by asterisks, none of these studies provides information about the correlation between transmission probability and number of sexual contacts (from R. M. Anderson and R. M. May, "Epidemiological Parameters of HIV Transmission," *Nature* 333 [1988]: 514–19, after Department of Health and Human Services, *HIV Infections in the United States: A Review of Current Knowledge and Plans for Expansion of HIV Surveillance Activities* [Washington, D.C.: Department of Health and Human Services, 1987], and other sources).

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difficulty that the infected sexual partner—the index case—is not necessarily the only way infection could have been acquired.

Of particular interest is the study by Peterman et al., which is the only published study to correlate transmission probability with number of sexual acts.[20] From a larger pool of individuals with transfusion-associated AIDS or HIV infection, Peterman et al. selected eighty infected individuals—fifty-five men and twenty-five women—and their spouses. Standard interviews were conducted with the index cases and their spouses so as to review their medical and social history; the study excluded all persons who had risk factors other than infected spouses. In particular, wives and husbands were asked about their sexual practices, about the average number of sexual contacts with their infected husbands or wives per month since the transfusion, and about changes in frequency of sexual contact after the partner had been diagnosed as having HIV seropositivity or AIDS. In all, Peterman et al. found that two of twenty-five husbands of infected wives, and ten of the fifty-five wives of infected husbands, were HIV seropositive. Figure 2 shows the relation between transmission of HIV infection and the number of sexual contacts with the infected spouse. The figure points to the surprising conclusion that transmission probability is unrelated to the actual number of sexual contacts for partnerships ranging from one to several thousand contacts. Insofar as there is any statistical correlation between transmission probability and number of contacts, it is negative (although not statistically significant): one infected woman had only a single sexual contact, and another had only 8; eleven of fifty-five wives and five of twenty-five husbands remained uninfected after more than 200 sexual contacts with their infected spouses. As discussed more fully elsewhere,[21] there were no correlations between kinds of sexual act, use of condoms, or the presence of a particular genetic marker (which had been suggested as predisposing to HIV infection) and the transmission of infection. Similar results have been obtained in an independent study in the United Kingdom.[22]

It has been suggested that the lack of correlation between transmission and levels of sexual activity shown in Figure 2 results from the possible brevity of infectious intervals, as just discussed (see Figure 1). But it is hard to see how the probability of hitting the center of the dart board is independent of the number of darts you throw, even if the dart board is smaller. We believe that if the patterns shown

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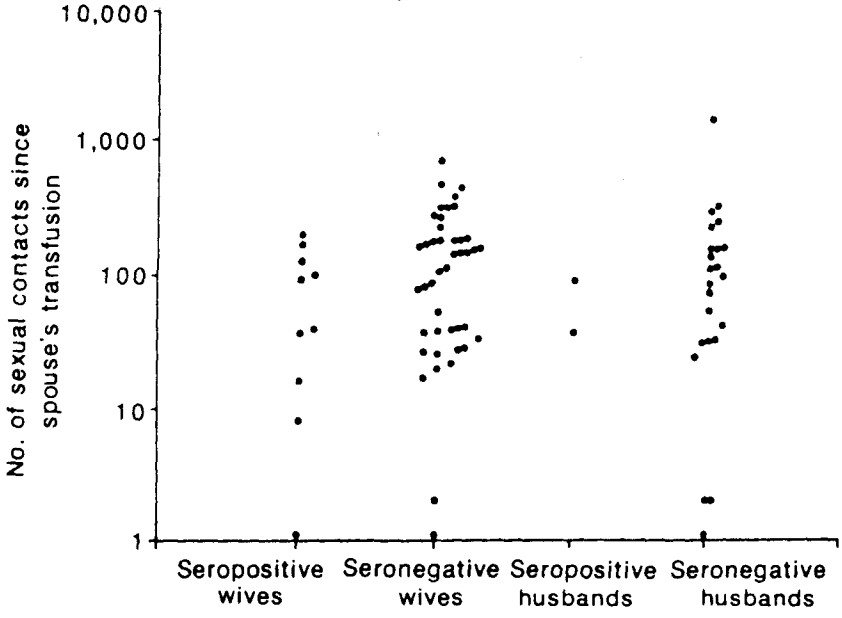
in Figure 2 continue to hold up under further studies and for other groups, then it is more appropriate to regard the transmission probability, β, as being some rough constant (with high variability)

Figure 2. Infection with HIV by Transfusion




For each of 80 individuals, this figure shows the number of sexual contacts with a spouse after the spouse was unknowingly infected with HIV by transfusion. The 25 husbands and 55 wives of infected individuals are divided according to current serological status. In this study group, transmission probability is not correlated with number of sexual contacts.

Source: R. M. May, "HIV Infection in Heterosexuals," *Nature* 331 (1988):655–56.

for partnerships of a given kind, rather than as increasing as $1-\exp(-\delta n)$ with the number of acts, n. In this context, it may be observed that the often-cited probability of around 1 in 1000 for acquiring HIV from an infected partner in one sexual act is nonsense; the number comes, in essentials, from using the data in Figure 2 to estimate an overall transmission probability of around 0.1 from partnerships typically comprising on the order of 100 sexual acts, each with transmission probability δ, compounded randomly; hence $\delta \simeq 0.001$. But the one thing the data in Figure 2 makes plain is that we are not dealing with a Poisson process here.

To put it another way, the patterns in Figure 2 have significant implications for epidemiological models. Most of the existing models assume some constant transmission probability per act, compound-

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ing in Poisson fashion. This means that, in the absence of precise knowledge about a partner's serological status, ten sexual acts with one partner carry the same risk as one sexual act with each of ten different partners. If, to the contrary, we take Figure 2 as saying that the transmission probability is essentially independent of the number of acts (for a given kind of partnership), then one act with each of ten people is clearly far more risky than ten acts with one person. These differences have clear implications for the conclusions we draw about likely rates of spread of infection within and between particular groups, and about the likely effects of different kinds of changes in behavior. It is very important that more studies like that summarized in Figure 2 be carried out, not only for heterosexual contacts but for other potentially infectious contacts. It would be valuable also to have a systematic exploration of possible correlations between transmission probabilities and other factors, such as the presence or absence of other infections, or of genital lesions associated with other sexually transmitted diseases (STDs).

Evidence about $\beta$ among male homosexuals is more indirect, and comes mainly from using epidemiological models to analyze serological data that is combined with information about rates of acquiring new partners.[23] The characteristic figure from studies with large sample sizes is again that $\beta$ is around 0.1 for unprotected receptive anal intercourse. Within these groups, there is a pronounced correlation between the number of different partners and the level of seropositivity, as suggested by mathematical models that take account of heterogeneity in degrees of sexual activity.[24] The rough equivalence between estimates of the transmission probability, $\beta$, for male homosexual partnerships and for the monogamous heterosexual partnerships in Figure 2 is a bit surprising and may exist because the transmission probability per act is higher for the former, but the average duration (and average number of acts) per partnership is compensatingly higher for the latter.

We are not aware of any quantitative estimates of transmission probabilities per needle-sharing act or partnership among drug abusers sharing needles. Such probabilities depend on the details of how needles are handled in relation to blood, and more information bearing on these questions is needed.

Overall, we note that patterns of incubation intervals and infectiousness depend mainly on the biology of the HIV virus and its

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interaction with the immune system, whereas transmission probabilities depend both on biology (rates of production of the virus and its presence in secretions and excretions) and on behavior (whether condoms are used and the extent to which blood is drawn back into a needle before passing it on). We now turn to the third component of $R_0$, namely the average rate of acquiring new partners, which is primarily a behavioral question.

## RATES OF ACQUIRING PARTNERS

Simple models for the transmission of HIV suggest that, for epidemiological purposes, the "effective" average rate of acquiring new sexual partners, c, should be interpreted not as the simple mean, m, of the observed distribution in rates, but rather as the mean-squared rate divided by the mean (in conventional statistical notation, $c=\langle i^2\rangle/\langle i\rangle$, where the sharp brackets denote averages over the observed distribution in rates of acquiring new partners[25]). This effective average rate of acquiring new partners may alternatively be written as $c=m+\sigma^2/m$, where $\sigma^2$ is the variance of the observed distribution of rates of partner change. This mathematical relation reflects the disproportionate role played by those at the high end of the partner-change distribution, who are more likely both to acquire and to transmit infection by virtue of their high activity levels. The above expressions are derived under the assumption that individuals within a defined group choose new sexual partners essentially at random, more active individuals being more likely to be chosen simply because they acquire partners at higher rates (an assumption epidemiologists call proportionate mixing). More generally, it may be that individuals tend to choose partners with levels of sexual activity similar to their own; such a departure from proportionate mixing, weighted according to sexual activity, will clearly tend to slow down the rate at which infection spreads from individuals in more sexually active classes to those in less active ones.[26]

Thus, at a minimum, we need to know the full distribution of rates of partner change in a defined risk group in order to calculate the effective average rate, c, for epidemiological purposes. For accurate analysis, however, we need full information not only about distributions in rates of acquiring partners but also about which activity level such partners typically come from.

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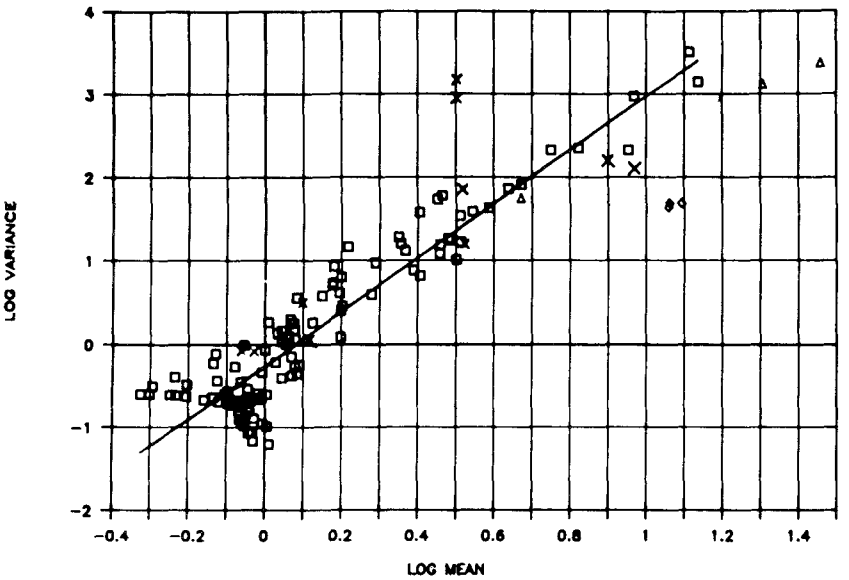
Such information about distributions in patterns of sexual activity, much less about networks of "who mixes with whom," is scant. Apart from anything else, it is not easy to get unbiased samples of

Figure 3a. Scatter Plot of Logarithm (Base 10) of Variance in Reported Numbers of Different Sexual Partners versus Logarithm of Mean Number of Sexual Partners from a Wide Range of Published and Unpublished Studies




The variances and means are drawn from studies that made use of many sampling methods, sampled various populations, and recorded numbers of different sexual partners over varying time intervals (ranging from the past month to a lifetime). The squares record data from surveys of heterosexual men and women in the general population of England and Wales; the crosses record data for heterosexual men and women attending sexually transmitted disease clinics in London; the triangles record data from male homosexuals in England and Wales; the diamonds record data on male heterosexuals from a rural community in a sub-Saharan African country. The solid line denotes the power law that gives the best least-squares fit, namely $\sigma^2 = am^b$ with $a = 0.56$, $b = 3.2$, excluding the data from Africa.

individuals who are willing to talk freely and accurately about their sex lives; in the words of Bateson and Goldsby, "we have spent centuries lying to ourselves about our own sexual activity and the activity going on around us."[27] Recent surveys show great variability in rates of acquiring new sexual partners, not simply between different risk groups and different countries or communities but among individuals in a given group.[28] The design and execution of surveys of sexual behavior clearly present many problems in sampling, assessment of reliability, and interpretation. It is therefore

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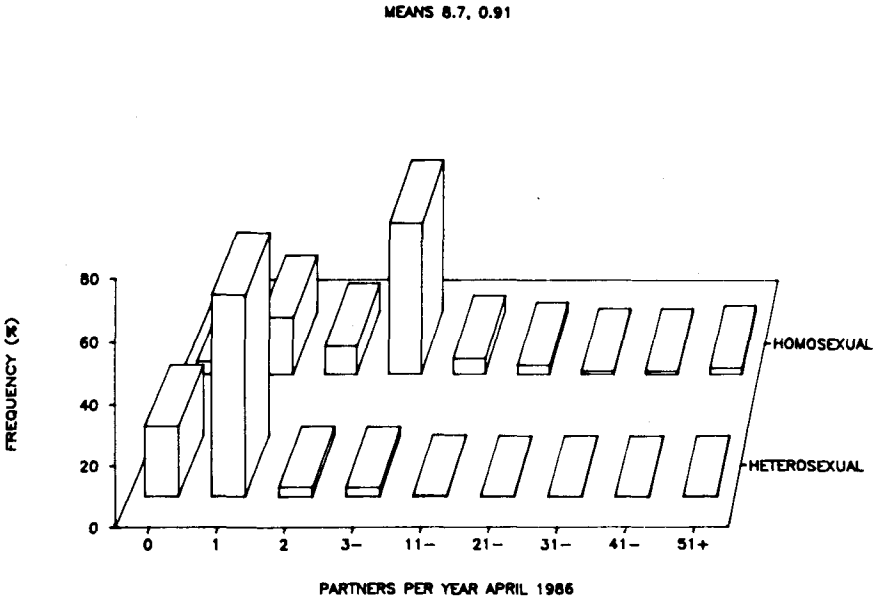
surprising that a wide range of surveys of different populations, based on a variety of sampling methods and time intervals for recall, shows a remarkably consistent pattern in the relation between the mean, m, and variance, $\sigma^2$, in the rate of acquiring new partners. This systematic pattern is illustrated in Figure 3a (on page 181), where $\sigma^2$

Figure 3b. Frequency Distributions of Number of Different Sex Partners Reported over a Year in Samples of Male Homosexuals and Male and Female Heterosexuals in England and Wales




Random location quota sampling was used, and the data were collected in April 1986. The data record number of different partners over the previous year. The mean numbers of reported partners were 8.7 and 0.91 for the homosexual and heterosexual samples, respectively.

and m are seen to be related by the power law $\sigma^2=am^b$ (where a and b are constants). In effect, this means that (for $b>1$, as is the case in Figure 3a), as the average rate of partner change increases from one group to another, the variance in the rates within the group increases disproportionately. We have no idea about the behavioral patterns that underlie the empirical relation documented in Figure 3a, although it does seem to us to be a promising avenue for further research.

In general, the information that is currently available shows higher rates of partner change among male homosexuals than among heterosexuals (see Figure 3b), among attendees at STD clinics than

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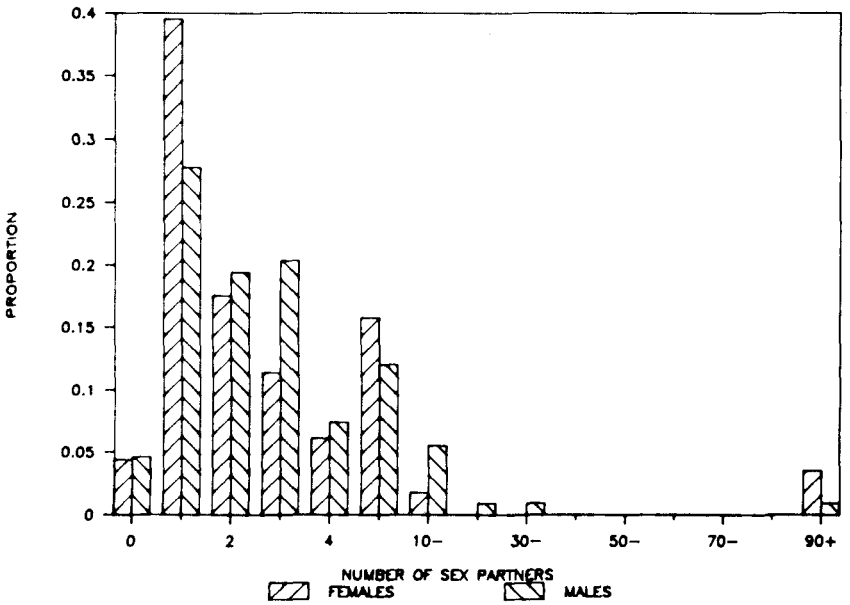
among members of the general population (see Figure 3c), among teenagers and young adults than among older people, and among males in certain sub-Saharan African countries than among males in

Figure 3c. Frequency Distributions of Number of Different Sexual Partners over Previous Year in Samples of Male and Female Heterosexuals Attending Sexually Transmitted Disease Clinics in London in March 1987




developed countries.[29] As may be expected, a history of past STD infection is often indicative of a high rate of partner change. The contrast between male homosexuals and heterosexuals in developed countries is often striking: a U.K. quota sample in April 1986, for example, suggested an eight-fold difference in the mean rates of change of sexual partners (see Figure 3b), which is consistent with surveys in the United States (Winkelstein et al.,[30] for example, found an average of 11 partners per year for a sample of 814 homosexual-bisexual men in 1984, while 212 heterosexual men in a corresponding sample averaged 2.8 female partners per year). Several surveys suggest, however, that in recent times male homosexuals have greatly reduced their rates of partner change; such changes are also reflected indirectly in decreases in the incidence of syphilis and rectal gonor-

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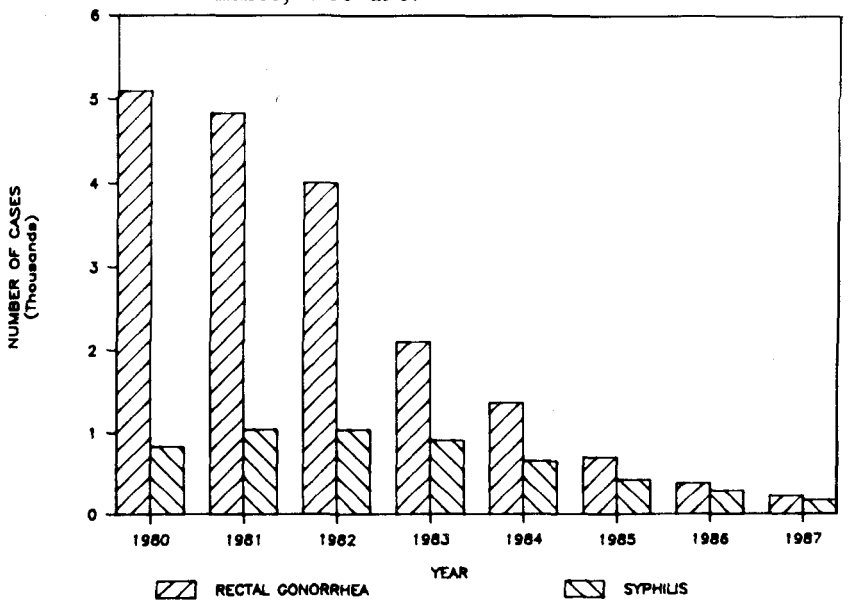
rhea in males (see Figure 3d), even though little change is found among heterosexuals in developed countries.

In particular, several studies of heterosexual behavior in the United States and the United Kingdom show unmarried men and women to

Figure 3d. Decline in Incidence of Rectal Gonorrhea in Males and of Primary or Secondary Syphilis in Homosexual Males in San Francisco, 1980–1987




Source: R. M. Anderson and R. M. May, "Epidemiological Parameters of HIV Transmission," *Nature* 333 (1988):514–19.

have, on average, more partners than married people, although typically 5 to 10 percent of married men and 2 to 5 percent of married women report sexual partners other than their spouses (for example, in the 1987 *Los Angeles Times* survey, roughly 40 percent of unmarried men reported 2 or more sexual partners over the previous year, as did 5.5 percent of married men; the corresponding figures were 15 percent for unmarried and 1.8 percent for married women[31]). These figures illustrate a problem that is common to essentially all such studies, namely that men report a significantly higher average number of partners than do women. This clearly cannot be the case. The extent to which the reported numbers reflect exaggeration by men, underestimation by women, or failure to

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capture a small but highly active fraction of the female population is usually not known.

Distribution patterns for sexual activity among men and women in countries in central Africa, where heterosexual transmission seems to be the main factor in the HIV-AIDS epidemic, are even less well studied than those in developed countries. We need to know much more about possible differences between rural and urban areas, and about the roles of female prostitutes and of truck drivers and others who move widely along lines connecting cities and villages. Recent seroprevalence levels among female prostitutes in Africa have been reported to range from 27 to 88 percent, depending on socioeconomic status and on geographic location; this group has clearly suffered disproportionately in acquiring HIV-AIDS infection and may correspondingly play a disproportionate role in transmitting infection.

TABLE 3. HIV Seroprevalence among Women Who Have Worked as Prostitutes since 1978 in Various Urban Locations in the United States

| Place | Sample size | Sources of cases | Fraction seropositive |
|---|---|---|---|
| Las Vegas | 38 | Brothel workers | 0.00 |
| Atlanta | 123 | Cases located on street or in detention center | 0.01 |
| Colorado Springs | 101 | STD clinic | 0.02 |
| Los Angeles | 338 | Detention center | 0.04 |
| San Francisco | 220 | Street | 0.05 |
| Miami | 471 | Jail | 0.14 |
| Southern New Jersey | 24 | ? | 0.21 |
| Northern New Jersey | 168 | Street and methadone clinic | 0.48 |

Sources: From *AIDS, Sexual Behavior and IV Drug Use*, report of the U.S. National Academy of Sciences' Committee on AIDS Research and the Behavioral, Social, and Statistical Sciences, ed. C. F. Turner. H. G. Miller, and L. E. Moses (Washington, D.C.: National Academy Press, 1988), after W. W. Darrow, *HIV Seroprevalence in Women Who Have Worked as Prostitutes since 1978*, CDC Document 0107X (Atlanta, Ga.: Centers for Disease Control, 1988), 1–5, where primary sources are cited.

The relation between female prostitutes and HIV in the United States is even less clear than in Africa. Table 3 shows how greatly varied the patterns are. Further analysis of the data in Table 3 shows that HIV infection among these prostitutes is found predominantly among those with histories of IV drug use; for 158 of the women in Table 3 there was evidence of IV drug use, and of these women 126,

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or roughly 80 percent, were HIV seropositive.[32] Of the women for whom there was no evidence of IV drug use, about 5 percent were infected with HIV (although roughly half these came from one site, Miami). The acquisition and analysis of data about the role that prostitutes could play in the transmission of HIV-AIDS cuts across other important policy concerns, particularly among feminists and sex researchers, about the place of prostitutes and prostitution in our society; research in this area, and attempts to engage prostitutes in helping to control the HIV-AIDS epidemic (as well as other STDs), must recognize the legitimacy of these concerns.

Clearly, further research on patterns of sexual activity in both developed and developing countries is in great need. We are amazed at the neglect this subject has suffered until recently. Such research will be most useful for epidemiological purposes if clear recognition is given to variability among and within groups and if surveys are accordingly designed to get as much information as possible about distributions of activity levels and about who mixes with whom. As we press forward in pursuit of such data, we should be wary of perpetuating an unfortunate tradition whereby concern about disease results in our treating some aspects of sexual conduct as a social or a medical problem; concern for the meaning and importance of sexuality in people's lives is not only right but likely to make our data gathering more effective.

For IV drug users, the corresponding information would seem to be the typical size of needle-sharing groups and the typical rate at which individuals enter and leave such groups. One study in Edinburgh suggests that needles may be shared among ten to twenty drug abusers.[33] The ethnography of needle sharing, however, differs greatly from place to place. Among some groups there is apparently a practice of drawing blood into the syringe to mix it with the drug for injecting; the ritual is sometimes to leave a little blood in the syringe (a token of sharing, as it were). In this event, the total number sharing the needle can be less important than the HIV status of the previous individuals using the needle. These complexities matter. We need more quantitative studies of patterns of needle sharing that combine the sensitivity of the anthropologist with the analytic approach of the epidemiologist.

Despite the growing number of small-scale surveys of sexual behavior in specific communities, there remains a need for large-scale

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national surveys (based on random sampling and performed at regular intervals), both to assess the potential for the spread of HIV-AIDS and to provide a baseline against which to assess the impact of changes brought about by education campaigns or other means.

## SEROLOGICAL SURVEYS

If we fully understood the distribution in the duration of infectiousness, the probability of infecting a partner, and numbers of new partners per unit time (as summarized by D, β, and c) within a particular group, we could construct a mathematical model for the overall transmission dynamics, test it against past serological trends, and then use it to project the likely course of the epidemic within that group under any assumption about future behavior. But, as we have just seen, we do not have anything like the detailed understanding that is needed. Under these circumstances, data about past and present levels of HIV seropositivity within a given group can be used in two ways. One is to use standard statistical methods to make extrapolations of past trends, obtaining short-term predictions of a purely phenomenological kind (without attempting to understand the underlying mechanisms). The other is to use such population-level data to make inferences about parameters such as β, c, and D, which characterize the epidemic at the level of individuals.

Figure 4 (on page 189) summarizes information about trends in HIV seroprevalence in various groups in various countries over the period 1978–1986. In the United States as of November 1987, some fifty studies of homosexual and bisexual men in different regions show seroprevalence levels ranging from under 10 percent to as high as 70 percent, most findings being between 20 percent and 50 percent. Among IV drug abusers, eighty-eight surveys and studies find seroprevalence ranging from highs of 50 to 65 percent in the vicinity of New York City and in Puerto Rico, to rates that—although variable—are mostly below 5 percent in areas other than the East Coast. For individuals requiring treatment with clotting factor concentrates, seroprevalence is around 70 percent for hemophilia A and around 35 percent for hemophilia B; throughout the United States, the rates are uniform, reflecting the lack of any significant geographical factor in the distribution of hemophilia. Among other special groups, some thirty-

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three studies of HIV prevalence among prisoners show levels ranging from 0 to 17 percent, which—as expected—were higher than among the general population but lower than among high-risk groups in the same general region. The data for female prostitutes in the United States were sketched above.

In the U.S. population as a whole, such data as are available suggest HIV seroprevalence levels of the general order of $10^{-3}$. For instance, Red Cross blood donors who have not previously been tested currently average 0.04 percent seropositive (a lower figure of around 0.02 percent is obtained if all donors are included, regardless of previous testing). Applicants for military service (whom the U.S. military believe to underrepresent persons in high-risk groups, although we do not share their certainty) run around 0.15 percent; much geographical variability is concealed within this overall average, which ranges from 0.96 percent of applicants in the District of Columbia, through 0.47 percent in Puerto Rico, 0.34 percent in New York, on down to very low figures in most midwestern states. Job Corps entrants ("disadvantaged" sixteen- to twenty-one-year-olds) average around 0.33 percent. Patients without AIDS-like conditions at four hospitals have seroprevalence levels around 0.32 percent. Childbearing women in Massachusetts (tested anonymously through filter-paper blood specimens from their newborn infants) ran around 0.21 percent. And twenty-seven surveys in women's health clinics (excluding drug users) produced levels ranging from 0 to 2.6 percent. The overall figure accords with the independent estimate of around 1 million to 1.5 million HIV infections within the U.S. population of around 240 million.[34] These overall figures are arrived at by adding up the estimated numbers in various categories of risk, along with rough estimates of seroprevalence levels in the various categories; the estimated number of homosexual males, for example, is still based on the old Kinsey study.[35]

Attempts have been made to refine the above U.S. data by removing those contributions to overall seroprevalence made by individuals in defined risk groups (homosexual and bisexual males, IV drug abusers, and so on). This refinement leads to the conclusion that "HIV prevalence levels in persons without acknowledged or recognized risks would be below 0.021% in military applicants and 0.006% in blood donors."[36] Limited studies of heterosexuals being treated for other STDs, but excluding those with identified risk

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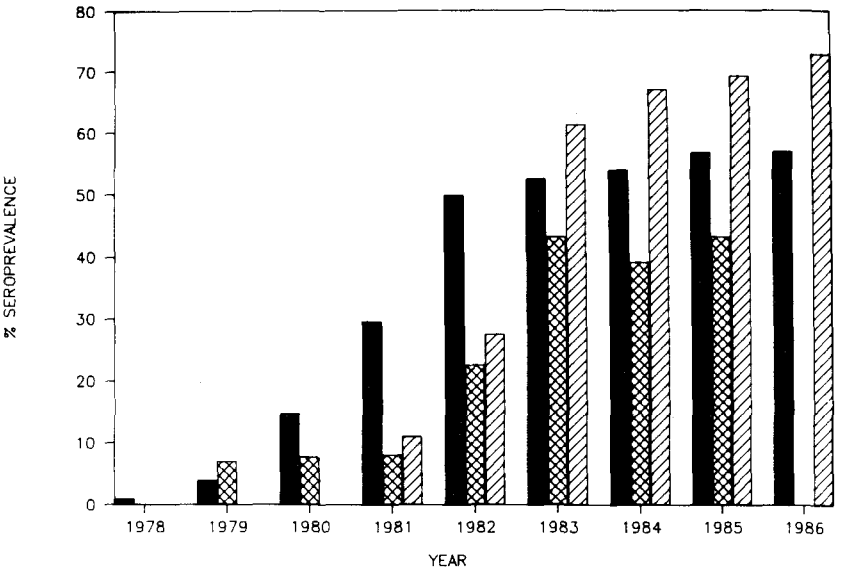
factors by rigorous protocols of interviews, find seroprevalence levels ranging from 0 to 1.2 percent (in comparison with over 50 percent for homosexual males attending the same clinic).

Figure 4. Changes in Percentage of Antibodies Specific to HIV Antigens that Were Seropositive in Longitudinal Studies of Homosexual and Bisexual Men in San Francisco and Intravenous Drug Users in Milan




In each set of histogram bars in this cohort study, the left-hand bar = male homosexuals and bisexuals in San Francisco; the middle, crosshatched bar = patients hospitalized for acute viral hepatitis in Milan; and the right-hand bar = patients in methadone maintenance treatment in Milan.

Source: R. M. Anderson and R. M. May, "Epidemiological Parameters of HIV Transmission," *Nature* 333 (1988):514–19.

In Africa, with transmission being mainly by heterosexual contacts, there is a different picture. In Nairobi, tests for HIV antibodies in blood serum stored from earlier studies (often for different purposes) show seropositivity levels among female prostitutes rising from 4 percent in 1980–1981 to around 51 percent in 1983–1984 and 59 percent in 1985–1986, and from 1 percent to 14 and 18 percent at the corresponding times for males attending a clinic for STDs.[37] In a general survey of pregnant women in Nairobi, seropositivity levels rose from 0 percent in 1980–1981 to 2 percent in 1985–1986; a similar survey of pregnant women in Kinshasa shows

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seropositivity levels rising from 0.2 percent in 1970 to 3 percent in 1980–1981 and 8 percent in 1985–1986.[38] A study of some 600 seronegative men and women working in a general hospital in Kinshasa from 1984–1985 found the annual incidence (or rate of seroconversion) of HIV antibodies to be around 0.8 percent, a figure that many think may be representative of the annual incidence of new HIV infections in central East Africa. Current studies of HIV seropositivity among blood donors in central African countries suggest levels as high as 9 percent in Zaire, 11 percent in Uganda, 15 percent in Rwanda, and 18 percent in Zambia.

The above figures for the United States come mainly from an excellent recent review of the data by the Centers for Disease Control (CDC). This study illustrates both the value of drawing together published and unpublished seroprevalence data and the desirability of nationwide surveys. There is need for similar compilations of surveys in other countries, preferably with international coordination.[39] In all such surveys, we believe the most important factors are the assessment of changes through time and at different spatial locations, in a consistent way; too often, data are aggregated before being made widely available, and therefore much of their usefulness diminishes.

Ideally, a study of the prevalence of HIV infection in a defined population would require drawing blood from a "probability sample" of individuals in that population (a procedure for which there exist well-defined statistical techniques), obtaining a blood sample, and then accurately testing for the presence of the HIV virus (actually, blood samples are tested for HIV antibodies, with the result that a recently infected individual may test negative because he or she has not yet developed measurable antibody titers). It would be even better if such seroprevalence data were coupled with information about each individual's sexual and other behavior. In reality, essentially all existing studies (as sketched above) are "samples of convenience," in which the study group is not only biased but often biased in ill-defined ways. One study group is a representative example: the 18 percent of individuals who refused to give blood were found to include more than half of those in the whole group with HIV infections, a fact determined by anonymous testing of unlabeled blood specimens that had been acquired earlier from the same people.[40]

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Among the measures that can help in gathering more accurate data are legal sanctions to preserve confidentiality and prevent discrimination (along with earnest efforts to ensure confidence that such protection will work), and/or testing of blood that has been obtained anonymously (usually for some other purpose). In particular, we think that blind surveys of blood samples from infants (which currently are nearly universally available for other purposes) are a promising source of relatively unbiased data because all babies—not some self- or otherwise-selected subset—furnish data. Such data, moreover, open a window on the seroprevalence among women of childbearing age, which is a large and important part of the sexually active population. An insightful and vastly more detailed account of these questions has recently been given by the U.S. National Academy of Sciences' Committee on AIDS Research and the Behavioral, Social, and Statistical Sciences.[41]

Indeed, well-designed surveys of the prevalence of other STDs can indirectly give helpful information, as seen in Figure 3d. That focus on HIV-AIDS has, in some places, taken resources away from other STDs is unfortunate both for its own sake and for the indirect information we are deprived of. Such data must, however, be interpreted cautiously, to guard against confusing correlation with causation. For instance, the observation that HIV infection is more prevalent in Africa among those with other STDs does not, by itself, prove that such other STDs facilitate transmission; we expect those with higher rates of partner change to be more at risk both for HIV and for other STDs.

Returning to the first paragraph in this section, we recall that one use of serological information is to project future trends. This can, however, be very difficult if the risk group in question is a relatively small and ambiguously defined part of a larger sample and if infection is spreading slowly (if at all) within the group. In particular, we believe great caution is needed in interpreting patterns of apparent stability in HIV prevalence among blood donors or military applicants: changing patterns of self-removal of individuals with risk factors, counterbalanced by new infections and further clouded by the possibility of a slowly spreading heterosexual epidemic (perhaps with a doubling time of six to fourteen years, given the observed differences in rates of sexual partner change between male homosexuals and heterosexuals), all roil together to offer many alternative

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explanations for the apparent steadiness. We do not believe that existing serological data can be used to rule out the possibility that HIV infection may be spreading slowly along purely heterosexual chains of transmission within some groups.

Such data can also be used to derive information about the quantities characterizing transmission from person to person. Thus, in the early phase of an epidemic, when most are still uninfected, we expect seropositivity levels to grow approximately exponentially, with the time taken for the number of seropositives to double (the so-called doubling time, $t_d$) being approximately related to the averaged parameters $\beta$, c, D that we defined earlier by the expression $t_d \simeq (\ln 2)/(\beta c - 1/D)$.[42] Table 4 lists such doubling times from different countries in the early stages of the epidemic; these doubling times are consistently around six to twelve months, which is a bit surprising considering the variability in sexual behavior (and thence in c and possibly $\beta$) that one might expect from place to place. If D is assumed to be at least two years and possibly more, then the numerical values for the doubling times given in Table 4 indicate that the product of the transmission probability times the epidemiologically effective average rate of acquiring new sexual partners is roughly one per year ($\beta c \sim 1 yr^{-1}$) for HIV transmission among homosexual males (the main group in Table 4). We have previously seen that $\beta \sim 0.1$ and $c \sim 10$, per year, for homosexual males in the United States and United Kingdom, but, paradoxically, these direct estimates of the individual quantities from serological data seem to be possibly more uncertain than the indirect inference of the magnitude of their product.

## PREDICTIONS AND UNCERTAINTIES

In this section, we give some explicit examples of ways in which the many uncertainties discussed above prevent us from answering important questions.

Growing evidence of HIV infection among heterosexual males and females with no known risk factors, other than being a regular sexual partner of an IV drug abuser or of a bisexual male (in the case of females), prompts the question of whether there will be a widely disseminated epidemic in heterosexual communities in developed countries. Although it is not possible to answer this question with any

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certainty at present, consideration of what we do know about components of the basic reproductive rate, $R_0$, for HIV provides some clues. Suppose the probability of transmission per partnership, $\beta$, is around 0.1, and that the average duration of infectiousness over

TABLE 4. Doubling Times for the Epidemic, Based on AIDS Cases Reported to the World Health Organization

| Country | Time Period | Doubling Time (in months) |
|---|---|---|
| Australia | 1986–1987 | 12.9 |
| Austria | 1983–1985 | 15.6 |
| Bahamas | 1986–1987 | 12.7 |
| Brazil | 1983–1985 | 8.5 |
| Canada | 1983–1985 | 12.7 |
| Dominican Republic | 1986–1987 | 6.4 |
| France | 1983–1985 | 11.2 |
| Greece | 1986–1987 | 7.8 |
| Jamaica | 1986–1987 | 5.8 |
| Kenya | 1986–1987 | 4.9 |
| Mexico | 1986–1987 | 7.5 |
| Netherlands | 1983–1986 | 11.2 |
| Portugal | 1986–1987 | 11.8 |
| South Africa | 1986–1987 | 11.8 |
| Spain | 1983–1986 | 6.3 |
| Sweden | 1983–1986 | 9.9 |
| Switzerland | 1983–1986 | 10.0 |
| Tanzania | 1986–1987 | 8.3 |
| United Kingdom | 1983–1986 | 14.0 |
| United States | 1981–1986 | 13.0 |
| Venezuela | 1986–1987 | 11.2 |
| Zambia | 1986–1987 | 13.9 |

Source: After R. M. May and R. M. Anderson, "The Transmission Dynamics of Human Immunodeficiency Virus," *Philosophical Transactions of the Royal Society* B 321 (1988), 565–607.

the long incubation period (around eight years) is on the order of two years, then for $R_0$ to exceed unity in value the effective rate of sexual-partner change, c (defined above by the relation $c=m+\sigma^2/m$), must be on the order of five or more per year. Data for the United Kingdom suggest typical means and variances in rates of partner change per year, in the general population, of around 0.5 to 1.5 and 1 to 5, respectively.[43] Thus, for the general population, the value of $R_0$ may be just above, or just below, unity. If it is just above (for example, $\beta=0.1$, $c=5.5\ yr^{-1}$, $D=2$ years, giving $R_0=1.1$), then the

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doubling time of the epidemic during the early stages could be on the order of eight to fourteen years (a figure to be contrasted with the one-year doubling time for the epidemic in the male homosexual population). It will therefore be extremely difficult to detect changes in seroprevalence in the general heterosexual population when, for example, the level of seroprevalence is a fraction of 1 percent (as it currently seems to be in the United States and the United Kingdom).

Our guess at values for the components of $R_0$ for HIV transmission in the heterosexual population is very crude, but one thing that is clear is the likelihood that the virus will spread in those groups having high rates of partner change. Attendees at STD clinics represent a group particularly at risk, given their above-average rates of change of sexual partners, along with the possibility that other STD infections increase the magnitude of $\beta$. A possible scenario for HIV spread is thus a very slow rise in seropositivity in the general population, on a time scale of decades, with infection largely restricted to the high end of the distribution of sexual activity. This may be too conservative a view if a proportion of those infected remains asymptomatic but infectious over very long periods of time (say ten years or more).

Figure 5 shows how these uncertainties affect long-term predictions based on models of viral transmission within and between risk groups. Using a model with variable incubation and infectious periods, and with heterogeneity in sexual activity, the figure illustrates the projected course of the epidemic among male homosexuals in the United Kingdom. As shown, the quantitative details of these projections are sensitive to assumptions concerning the fraction who develop AIDS, the average incubation period, and the mean and variance of the rate of sexual-partner change (and how the mean and variance may change over time). The timing of the peak incidence of AIDS from the start of the epidemic is largely set by the average incubation-infectious period and by the magnitude of $R_0$. The total epidemic is, however, made up of a series of waves passing successively through the different sexual activity groups; those with high rates of partner change are infected early on, and those with low rates much later. Similarly, seroprevalence (the fraction infected) is high in high partner-change groups and low in low partner-change groups. During the course of the epidemic, the average rate of change of sexual partners in the population will decline as a consequence of the early infection and death from AIDS of the individuals with high

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rates. This trend will occur independently of any change in the sexual behavior of individuals and can clearly complicate the assessment of such induced changes.

The increasing spread of HIV-AIDS among the general heterosexual population in large parts of central Africa raises questions about the long-term implications for overall rates of population growth, possible changes in age structure, and other demographic and economic characteristics of such populations. These questions can be studied by combining conventional demographic models with epidemiological models for HIV transmission and AIDS mortality. In our own work we have used deliberately oversimplified models that permit a qualitative understanding of the variety of results that are produced by different choices of demographic and epidemiological parameters; on the basis of this understanding, we have then made numerical computations for more detailed models.[44] Our conclusion is that HIV-AIDS in central Africa is capable of significantly reducing overall rates of population growth, which currently run around 3 percent per annum, and could even lead to negative growth rates. The magnitude of the long-term effects, even assuming no behavioral changes, are uncertain, because so many of the determining factors—$\beta$, c, D, f (the fraction of those infected who go on to develop AIDS), and the fraction of offspring born to infected mothers who acquire HIV-AIDS by vertical transmission—are uncertain. The effects on age structure are likely to be even more complex, with the direct effects of adult deaths tending to increase the child-dependency ratio (essentially, the ratio of children to adults), while the indirect effects of increasing mortality and decreasing fecundity (resulting from infant deaths from vertically transmitted AIDS) mean slower population growth and thus less steep age profiles, tending to decrease the child-dependency ratio. These countervailing effects tend, however, to cancel out, over a wide range of parameters.

Interestingly, other studies of the likely demographic impact of HIV-AIDS in Africa[45] find somewhat less impact on growth rates than we do. These studies are based on assuming a constant probability of transmission per sexual act, with probability of order $10^{-3}$ (whereas we choose the probability as being per partnership, and we estimate the parameter combination $\beta c$ from observed doubling times for HIV seropositivity in Africa rather than using indirect inferences about $\beta$ and c separately, as discussed earlier). It seems

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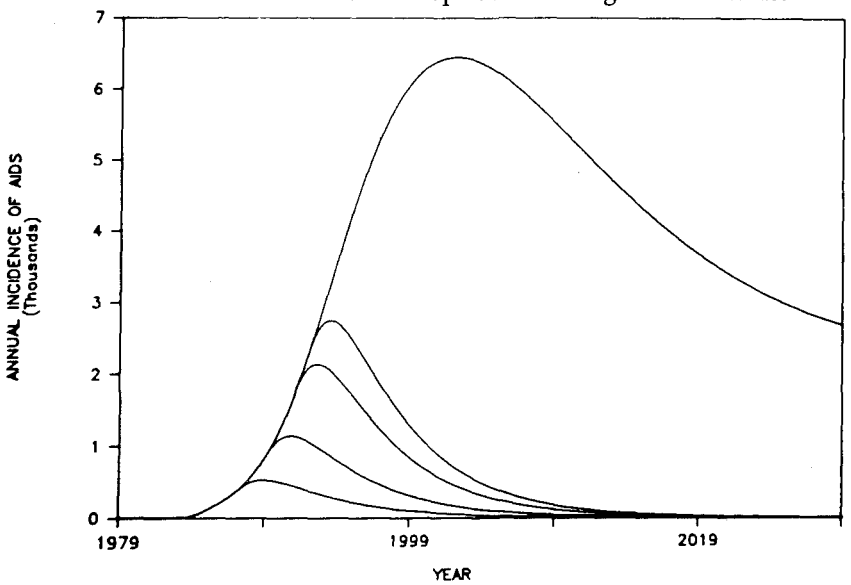
likely that our way of dealing with this aspect of transmission dynamics assigns a greater role to female prostitutes and thus shows

Figure 5. Numerical Simulations of the AIDS Epidemic in the Male Homosexual-Bisexual Population of England and Wales




The projections are based on a hybrid model that incorporates distributed infectious and incubation periods (a mean of 8 years with an early phase of infectiousness lasting 6 months, with $\beta_0 = 0.035$, and a late phase lasting 1.5 years with $\beta_1 = 0.07$) and heterogeneity in sexual activity.* The mean and variance of the sexual activity distribution are defined by the power law relationship recorded in the legend in Figure 3a. The epidemic was initiated in 1979 by the introduction of one infectious male (first episode) in a class with high sexual activity (20–50 partners per year), into an estimated population of 500,000 homosexual and bisexual men (4 percent of the sexually active male population between the ages of 16 and 56). In 1979 the mean rate of partner change was assumed to be 8 years$^{-1}$. This average was assumed to decline to 6 in 1982, to 4 in 1984, and to 3.5 in 1987. The projected number of cases closely mirrors observations over the 1979–1987 period in England and Wales. In the top line the mean rate of partner change was assumed to remain constant at 3.5 years$^{-1}$ for the remaining years of the simulation. From the bottom line to the second from the top in year 1999, transmission was halted (by the mean rate of partner change declining to 1.0 year$^{-1}$ such that $R_0 < 1$) in 1987, 1989, 1991, and 1992, respectively. Note how the projected incidence of AIDS depends critically on current patterns of sexual partner change and the large number of cases of AIDS that will appear in future years even after transmission of HIV is halted.†

*Source: S.P. Blythe and R.M. Anderson, "Distributed Incubation and Infectious Periods in Models of the Immunodeficiency Virus," *IMA Journal of Mathematically Applied Medical Biology* 5 (1988):1–19.

†Source: R. M. Anderson and R. M. May, "Epidemiological Parameters of HIV Transmission," *Nature* 333 (1988):514–19.

faster and more widespread dissemination of infection than do models where each act with an infected individual has very low

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probability of transmitting infection; hence our estimate of greater demographic impact. As emphasized above, neither of these contrasting approaches can be ruled out on current evidence. These biological uncertainties are compounded by lack of quantitative information about social patterns in central African cities and villages (such as numbers of sexual partners and movements among cities and villages), clouding all long-term predictions.

## CONCLUSIONS

It is not surprising that many uncertainties still surround the key epidemiological parameters determining transmission within and between different risk groups, given the very long incubation period of AIDS and the primary modes of transmission of HIV. Epidemiological data are improving, but there are important gaps in our understanding. These could be filled by more determined attempts, at national levels, to promote, adequately support, and coordinate large-scale, long-term studies of: (1) changes in seroprevalence through time, both in cohorts and in the general population; (2) sexual life-styles and behavior (which is of particular importance in developing countries at present); and (3) the infectiousness of infected people. Such studies should include measurements of fluctuations in viral abundance in blood, secretions, and excretions, along with immunological scores of the progression of disease and of genetic changes in the virus population.

A better epidemiological understanding is a prerequisite for the design of trials for promising candidates for vaccines or drugs. It is also insurance against failure to develop vaccines or effective drugs. The problems associated with testing a candidate vaccine are daunting but would be less so if more were understood about infectiousness and transmission. It remains to be proven that azidothymidine or any other drug suppresses the infectiousness of treated patients. Unfortunately, any drug that prolongs survival could in principle enhance the transmission potential (by increasing D) of an infected person. The main hope for preventing a heterosexual wave of the epidemic in developed countries, given the failure to prevent extensive spread in the male homosexual and IV drug-using populations, remains education and publicity. Without firm commitment and intensive effort, it is likely to be difficult to maintain public interest in

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the face of what could yet be a very slowly developing heterosexual epidemic.

In all this, we need to remain vividly aware that there is great variability in behavior (and possibly in biological responses to HIV infection) within and between groups. As we have seen (for example, in Figures 3 and 5), the dynamics of transmission—including such basic things as the shape of the curves describing the initial rise in seropositivity or in AIDS cases—depends on the details of such variability. There are, of course, many ethical and social reasons why we should not deal with individuals in terms of stereotyped risk groups. We therefore believe it is all the more important to recognize that mathematical models reinforce these concerns. In a precise epidemiological and mathematical sense, sexual contacts or needle sharing within a group cannot accurately be characterized by "average" individuals or "average" behavior, but rather we must have quantitative information about the range of behavior (and, preferably, the full distribution of behavior).

We conclude on a somewhat more controversial note. Many of the difficulties associated with acquiring serological or other data, and even with using existing sources of data, stem from legitimate concerns for the privacy and rights of infected individuals. There is clearly a moral obligation, and in our view there should also be an unambiguous legal obligation, to prevent unwarranted discrimination against those infected with HIV. On the other hand, excessive precautions have, on occasion, rendered data inaccessible. Such inaccessibility of information potentially sacrifices the rights of invisible individuals—the HIV infections waiting downstream in time, as it were—some of whom might be spared if we understood the epidemic better. Conflicting concerns of this kind are as old as humanity itself. We believe, however, that we should stretch hard to find acceptable ways of making all data available and of systematically acquiring new data. We should not wait until people actually become infected with HIV before we acknowledge their rights.

ENDNOTES

[1]T. C. Quinn, J. M. Mann, J. W. Curran, and P. Piot, "AIDS in Africa: An Epidemiological Paradigm," *Science* 234 (1989):955–63.

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[2]H. Hethcote, "AIDS Modeling in the USA," in *Future Trends in AIDS* (London: Her Majesty's Stationery Office, 1987), 35–41.

[3]Department of Health and Human Services, *HIV Infections in the United States: A Review of Current Knowledge and Plans for Expansion of HIV Surveillance Activities*, report to Domestic Policy Council (Washington, D.C.: Department of Health and Human Services, 1987).

[4]R. M. Anderson and A. M. Johnson, "Rates of Sexual Partner Change in Homosexual and Heterosexual Behaviour in Relation to AIDS," in *Kinsey Institute Conference on Sexual Behaviour in Relation to AIDS*, ed. B. Boller (New York: Oxford University Press, 1988).

[5]Quinn et al.

[6]G. F. Medley, R. M. Anderson, D. R. Cox, and L. Billard, "Incubation Period of AIDS in Patients Infected via Blood Transfusion," *Nature* 328 (1987):719–21; and idem, "The Distribution of the Incubation Period of AIDS," in *Proceedings of the Royal Society*, B233 (1988), 367–77.

[7]J. W. Curran, H. W. Jaffe, A. M. Hardy, W. M. Morgan, R. M. Selik, and T. J. Dondera, "Epidemiology of HIV Infection and AIDS in the United States," *Science* 239 (1988):610–16.

[8]G. F. Medley, R. M. Anderson, D. R. Cox, and L. Billard, "Estimating the Incubation Period for AIDS Patients," *Nature* 333 (1988):504–5.

[9]M. F. Rogers, P. A. Thomas, E. T. Starcher, and M. C. Noa, "AIDS in Children: Report of the CDC National Surveillance," *Paediatrics* 79 (6) (1987):1008–14.

[10]R. M. Anderson and R. M. May, "Epidemiological Parameters of HIV Transmission," *Nature* 333 (1988):514–19.

[11]Curran et al.

[12]R. Rothenberg et al., "Survival with Acquired Immunodeficiency Syndrome," *New England Journal of Medicine* 317 (1987):1297–1302.

[13]G. Reeves and S. E. Overton, "Average Survival Times for AIDS Patients in the UK," *Lancet* 1 (1988):880.

[14]P. Piot, F. A. Plummer, F. S. Mhalu, J. L. Lamborany, J. Chin, and J. M. Mann, "AIDS: An International Perspective," *Science* 239 (4840) (1988):573–80.

[15]C. Pederson, C. M. Nielson, B. F. Vestergaard, J. Gerstoft, K. Krogsgaar, and J. O. Nielson, "Temporal Relation of Antigenaemia and Loss of Antibodies to Core Antigens to Development of Clinical Disease of HIV Infection," *British Medical Journal* 295 (1987):567–69; and J. Goudsmit and D. A. Paul, "Circulation of HIV Antigen in Blood According to Stage of Infection, Risk Group, Age and Geographic Origin," *Epidemiology and Infection* 3 (1987):701–11.

[16]R. M. May and R. M. Anderson, "The Transmission Dynamics of Human Immunodeficiency Virus," in *Philosophical Transactions of the Royal Society*, B321 (1988):565–607; R. M. May, R. M. Anderson, and A. R. McLean, "Possible Demographic Consequences of HIV/AIDS: I, Assuming HIV Infection Always Leads to AIDS," *Mathematical Bioscience* 90 (1988):475–505; and S. P. Blythe and R. M. Anderson, "Distributed Incubation and Infectious Periods in

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Models of the Immunodeficiency Virus," *IMA Journal of Applied Medical Biology* 5 (1988):1–19.

[17]M. C. Bateson and R. A. Goldsby, *Thinking AIDS* (Reading, Mass.: Addison-Wesley, 1988).

[18]Anderson and May.

[19]Anderson and Johnson; Centers for Disease Control, "Antibody to Human Immunodeficiency Virus in Female Prostitutes," *Morbidity and Mortality Weekly Report* 36 (1987):157–61; and R. M. May, "HIV Infection in Heterosexuals," *Nature* 331 (1988):655–56.

[20]T. A. Peterman, R. L. Stoneburner, J. R. Allen, H. W. Jaffe, and J. W. Curran, "Risk of HIV Transmission from Heterosexual Adults with Transfusion-associated Infections," *Journal of the Americal Medical Association* 259 (1988): 55–63.

[21]Ibid.; and R. M. May, "HIV Infection in Heterosexuals," *Nature* 331 (1988): 655–56.

[22]Johnson, private communication.

[23]R. M. Grant, J. A. Wiley, and W. Winkelstein, "Infectivity of the Human Immunodeficiency Virus: Of Homosexual Men," *Journal of Infectious Diseases* 156 (1987):189–93.

[24]R. M. May and R. M. Anderson, "Transmission Dynamics of HIV Infection," *Nature* 326 (1987):137–42; and idem, "The Transmission Dynamics of Human Immunodeficiency Virus."

[25]R. M. Anderson, G. F. Medley, R. M. May, and A. M. Johnson, "A Preliminary Study of the Transmission Dynamics of the Human Immunodeficiency Virus, the Causative Agent of AIDS," *IMA Journal of Applied Medical Biology* 3 (1986):229–63; and May and Anderson, "Transmission Dynamics of HIV Infection."

[26]J. M. Hyman and E. A. Stanley, "A Risk-based Model for the Spread of the AIDS Virus," *Mathematical Bioscience* 90 (1988):415–73; J. A. Jacquez, C. P. Simon, J. Koopmen, L. Sattenspiel, and T. Perry, "Modeling and Analysing HIV Transmission: The Effect of Contact Patterns," *Mathematical Bioscience* 92 (1988):119–99; and S. P. Blythe and C. Castillo-Chauvez, "Like-with-Like Preference and Sexual Mixing Models," (forthcoming).

[27]Bateson and Goldsby.

[28]S. P. Blythe and R. M. Anderson, "Distributed Incubation and Infectious Periods in Models of the Immunodeficiency Virus," *IMA Journal of Applied Medical Biology* 5 (1988):1–19; and N. H. Steigbigel, P. W. Maude, and C. J. Feiner, "Heterosexual Transmission of Infection and Disease by the Human Immunodeficiency Virus (HIV)," Third International Conference on AIDS, Washington, D.C., 1987.

[29]Blythe and Anderson.

[30]W. Winkelstein, M. Sammuel, N. S. Padian, and J. A. Wiley, "Selected Sexual Practices of San Francisco Heterosexual Men and Risk of Infection by HIV," *Journal of the American Medical Association* 257 (1987):1470–71.

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[31]NAS, *AIDS, Sexual Behavior and IV Drug Use*, a report of the NAS Committee on AIDS Research and the Behavioral, Social, and Statistical Sciences, ed. C. F. Turner, H. G. Miller, and L. E. Moses (Washington, D.C.: National Academy Press, 1988).

[32]W. W. Darrow, *HIV Seroprevalence in Women Who Have Worked as Prostitutes since 1978*, CDC Document 0107X (Atlanta, Ga.: Centers for Disease Control, 1988), 1–5.

[33]J. R. Robertson, A. B. V. Bucknall, and P. D. Welsby, "Epidemic of AIDS-related Virus (HTLVII/LAV) Infection among Intravenous Drug Abusers," *British Medical Journal* 292 (1986):527–29.

[34]U.S. Public Health Service, "U.S. Public Health Coolfont Report," *Public Health Reports* 101 (1986):341–48; and Department of Health and Human Services.

[35]A. C. Kinsey, W. B. Pomeroy, and C. E. Martin, *Sexual Behavior in the Human Male* (Philadelphia: Saunders, 1948).

[36]Department of Health and Human Services.

[37]Quinn et al.

[38]Ibid.

[39]S. P. Layne, T. G. Marr, S. A. Colgate, J. M. Hymann, and A. E. Stanley, "The Need for National HIV Databases," *Nature* 333 (1988):511–12.

[40]NAS.

[41]Ibid.

[42]Anderson et al., "A Preliminary Study"; and May and Anderson, "Transmission Dynamics of HIV Infection."

[43]Anderson and Johnson.

[44]R. M. Anderson, R. M. May, and A. R. McLean, "Possible Demographic Consequences of AIDS in Developing Countries," *Nature* 332 (1988):228–34; May et al., "Possible Demographic Consequences of HIV/AIDS: I"; and R. M. May, R. M. Anderson, and A. R. McLean, "Possible Demographic Consequences of HIV/AIDS Epidemics: II, Assuming HIV Infection Does Not Necessarily Lead to AIDS," in *Proceedings of the International Symposium in Mathematical Approaches to Ecological and Environmental Problem Solving*, ed. C. Castillo-Chauvez, S. A. Levin, and C. Shoemaker (New York: Springer-Verlag Lecture Notes in Biomathematics, forthcoming).

[45]Private communication with John Bongaarts, Director of the Research Division at the Population Council in New York City, and with Meredith John, Assistant Professor of Food Research at Stanford University.

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Summer 1987

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